

# HEALTH AND HUMAN RIGHTS RESOURCE GUIDE



**FXB**CENTER  
FOR HEALTH & HUMAN RIGHTS

HARVARD SCHOOL OF PUBLIC HEALTH | HARVARD UNIVERSITY

# HEALTH AND HUMAN RIGHTS RESOURCE GUIDE

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## Health and Human Rights Resource Guide

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Fifth Edition, November 2013

Cover photograph courtesy of Sven Torfinn - Panos for the Open Society Foundations, "A paralegal nurse named Mercy and a lawyer named Johnson, both with Nyeri Hospice in Nyeri, Kenya talk with Elizabeth (center) about her health and property. She has cancer and is cared for by her granddaughter Caroline (to her left). She wants to ensure her granddaughters can inherit her property even though other relatives are trying to claim it."

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# INTRODUCTION



## HEALTH AND HUMAN RIGHTS

“ [The right to health is] an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information ... ”

– *Committee on Economic, Social and Cultural Rights, General Comment No. 14*

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The following people drafted, contributed, or commented on materials for the individual chapters of the Guide:

## **Introduction**

Arlan Fuller, Oscar Cabrera, Angela Duger

### **1. Patient Care and Human Rights**

Angela Duger, Jennifer Leaning, Sarah Dougherty, Judy Overall, Tamar Ezer

### **2. HIV, AIDS, and Human Rights**

Angela Duger, Sarah Dougherty, Till Baeringhausen, Ralf Jurgens

### **3. TB and Human Rights**

Sarah Dougherty, Allan Maleche, Angela Duger, Evan Lyon, Erin Howe, Anya Sarang

### **4. Harm Reduction and Human Rights**

Angela Duger, Damon Barrett, Sarah Dougherty,

### **5. Palliative Care and Human Rights**

Angela Duger, Jennifer Leaning, Sarah Dougherty, Tamar Ezer

### **6. Children's Health and Human Rights**

Nadia Ben-Youssef, Ali Yamin, Angela Duger, Sarah Dougherty, Tamar Ezer

### **7. Minority Health and Human Rights**

Angela Duger, Margareta Matache, Sarah Dougherty, Alina Covaci, Alpha Abdikeeva, Tamar Ezer

### **8. LGBTI Health and Human Rights**

Claire Mahon, Tim Fletcher, Charles Dallimore, Angela Duger, Sarah Dougherty, Heather Doyle

### **9. Disability, Health, Community Living and Human Rights**

Angela Duger, Heather Adams, Alison Hillman, Tirza Leibowitz, Judith Klein

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# PREFACE

The FXB Center for Health and Human Rights at Harvard University (FXB Center) is honored by the invitation from Open Society Foundations (OSF) to update the Health and Human Rights Resource Guide. The Center appreciates this opportunity to advance the global discussion on health and human rights by working on the new edition of the Resource Guide with OSF, a leader in civil society. This work aligns with the FXB Center's mission to promote knowledge, develop networks, and make positive change in the health and wellbeing of people worldwide.

As an academic center, FXB has launched a number of research and policy initiatives that have helped improve the health and well-being of people trapped in grave poverty, conflict, disease, and social marginalization. By engaging with major international institutions and non-governmental organizations, the Center expanded the understanding of rights, and contributed to removing legal and social barriers to human rights enforcement worldwide.

This Resource Guide is intended to promote knowledge of rights by bridging the gap between theory and practice. We hope that ongoing and future collaboration between and among the FXB Center, OSF and our local partners will increase our collective effectiveness in protecting the most vulnerable and assisting them to fulfill their rights. On behalf of all the contributors to this updated Resource Guide, I extend the hope that those working to defend and secure human rights will find the new Guide a useful addition to their advocacy tools.

Sincerely,

Jennifer Leaning  
Director  
FXB Center for Health and Human Rights  
Harvard University



# ABOUT THIS GUIDE

## Objective

This Resource Guide is a practical reference tool intended to serve as an introduction to the issue areas covered in each chapter. It has been designed for a wide array of users: health workers, trainers, program designers, litigators, and policymakers. Readers are encouraged to refer to other authoritative sources when conducting in-depth research on a specific topic.

The Resource Guide has been designed to be a user-friendly, multi-purpose tool in advocating for health and human rights. To ensure easy and widespread access, the Guide is available online in both HTML and PDF formats. This allows both a web-friendly version, as well as a print-friendly version, for use in any context. The Resource Guide has also been translated into multiple languages, all of which are available online.

## Purpose

The Resource Guide can be used for many different purposes. These include:

- **Collaborating with colleagues on strategy development**
  - The Resource Guide provides many examples of human rights violations and different strategies for advancing health and human rights. These can serve as an inspiration for an organization's strategy development. The Resource Guide also provides many examples of collaboration between law-focused and public health staff to advance health and human rights.
- **Developing regional or thematic courses and trainings**
- **Educating other funders**
- **Identifying human rights claims**
  - The Resource Guide provides many examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies.
- **Adapting the case examples in your country**
  - The case examples can serve as a model for others who work on those related issues. Case examples can also be shared with partners or funders to encourage new projects or programs on health and human rights issues.
- **Conduct further research**
  - The resources provided are intended to help guide readers to authoritative sources on specific topics. These lists can be helpful when writing an article or news press, preparing a presentation, or drafting a proposal.



## Organization

The Resource Guide covers basic concepts in health and human rights. This Introduction provides a primer on the right to health and human rights, an introduction to human rights-based approaches to policy and programming, an introduction to human rights mechanisms, and general resources on health and human rights. The other nine chapters each focus on a different health issue or marginalized or vulnerable population. The nine chapters do not reflect an exhaustive list of health and human rights issue areas. Rather they highlight priority program areas of the FXB Center and Open Society Foundations.

Each chapter is organized into six sections. These sections are listed below, together with a description of their purpose and how they can be used:

**1. How is this topic a human rights issue?**

- This section provides an introduction to the issue area and a description of why it is a human rights issue. Some chapters also include a description of common human rights-based approaches to the issue.

**2. What is a human rights-based approach to advocacy, litigation, and programming?**

- This section, common to each chapter, describes the key elements of a human rights-based approach. It also describes the different methods available for using a rights-based approach and the benefits that ensue.

**3. What are the most relevant international and regional human rights standards related to this issue?**

- This section provides two sets of tables. The first set (Tables A and B) provides a quick reference to the relevant articles in international and regional human rights instruments referred to in the text. The second set of tables are numerically labeled (Table 1 and on) and each is dedicated to an individual human right. Each individual table lists examples of human rights violations as well as international and regional treaty body interpretation and case law interpreting the human right. For example, Table 3 in the patient care chapter is “Patient care and the right to information.”
- These tables are helpful for constructing human rights arguments, identifying opportunities for using human rights mechanisms, or doing human rights legal research.

**4. What are some examples of effective human rights programming on this issue?**

- This section provides examples of effective litigation and advocacy activities. They are intended as suggestive precedents to be applied as needed in the particular context at hand.

**5. Where can I find additional resources on this issue?**

- The resources section provides a list of human rights instruments, topical resources, training materials and websites on specific human rights issue. Most of the resources are available online (websites are provided) and are open source. In some cases, the resources are available in multiple languages.

**6. What are key terms related to this issue?**

- The glossary provides generally accepted definitions of key terms utilized within the chapter or commonly used within the field.

# INTRODUCTION TO HEALTH AND HUMAN RIGHTS

## The Right to Health

### Legal Basis for the Right to Health

The right to health is widely recognized in international human rights law. Below is a chart of the international and regional human rights instruments expressly recognizing the right to health:

Human Rights Instrument	Right to Health Provision
Universal Declaration of Human Rights	Article 25
International Covenant on Economic and Social Rights	Article 12
International Convention on the Elimination of All Forms of Racial Discrimination	Article 5 (d) (iv)
Convention on the Elimination of All Forms of Discrimination Against Women	Article 11.1(f) and 12
Convention on the Rights of the Child	Article 24
Convention on the Rights of Persons with Disabilities	Article 25
African Charter on Human and Peoples' Rights	Article 16
European Social Charter	Article 11
American Declaration of the Rights and Duties of Man	Article XI
Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights	Article 10

The mostly widely used and comprehensive articulation of the right to health is set out in the International Covenant on Economic, Social, and Cultural Rights (ICESCR). ICESCR Article 12 provides that “The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”<sup>1</sup>

The Committee on Economic, Social and Cultural Rights (CESCR) is the UN body authorized to monitor compliance with the ICESCR and has issued a general comment on the right to health – General Comment 14.<sup>2</sup> General comments provide authoritative guidance on how States Parties to a treaty are expected to implement their treaty obligations. However General Comments are not binding on States Parties. This means that States are not legally obligated to comply with the General Comments. (For more information on this distinction, please see page XX of the Introduction.)

<sup>1</sup> UN General Assembly, *International Covenant on Economic, Social, and Cultural Rights* (ICESCR) (Dec 16, 1966, entered into force Jan 3, 1976). <http://www.refworld.org/cgi-bin/telex/vtx/rwmain?docid=3ae6b36co>.

<sup>2</sup> Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

# CESCR General Comment 14 on the Right to Health

## **Normative Content**

The right to health is short-form for the right to the highest attainable standard of physical and mental health. The right to health is not the right to be healthy or the right to health care, but a more complex and nuanced understanding of the right to health. CESCR explains that “the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health. This section focuses on how CESCR has defined and explained what the right to health is (the normative content), States Parties’ obligations, and recommendations for national implementation of the right to health.

## ***Underlying Determinants of Health***

CESCR General Comment 14 explains that the “right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health.” In other words, the underlying determinants of health can be thought of as “a wide range of socio-economic factors that promote conditions in which people can lead a healthy life.” CESCR explains that the underlying determinants of health include, but are not limited to:

- Adequate supply of safe food and nutrition
- Housing
- Access to safe and potable water and adequate sanitation
- Safe and healthy working conditions
- Healthy occupational and environmental conditions
- Access to health-related education and information including on sexual and reproductive health.

### ***Essential Elements of the Right to Health***

The following is a list of essential elements applicable to all aspects of the right to health, including the underlying determinants, and to all countries, “the precise application of which will depend on the conditions prevailing in a particular” country.

#### **A) Availability**

- Public health and health care facilities, goods, services and programs are available in sufficient quantity and include 1) the underlying determinants of health including drinking water and sanitation facilities, 2) hospitals, clinics or other health-related buildings, 3) trained medical and professional personnel, and 4) essential drugs.

#### **B) Accessibility**

##### *1. Non-discrimination*

- Health facilities, goods and services accessible to all, especially marginalized and vulnerable populations.
- Discrimination is prohibited on the grounds of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status.

##### *2. Physical accessibility*

- Health facilities, goods and services, medical services, and the underlying determinants of health are all provided within safe physical reach for all sections of the population.

##### *3. Economic accessibility (affordability)*

- Health facilities, goods and services are affordable for all.
- Health care services and services related to the underlying determinants of health must be based on equity, meaning affordable for all and not disproportionately burdensome for the poor .

##### *4. Information accessibility*

- Information is accessible and includes the right to seek, receive and impart information and ideas on health issues, while respecting the right to confidential personal health data.

#### **C) Acceptability**

- Health facilities, goods and services are respectful of medical ethics and culturally appropriate including sensitive to gender and life-cycle requirements.

#### **D) Quality**

- Health facilities, goods and services are scientifically and medically appropriate and of good quality. This includes skilled medical personnel, scientifically approved drugs and hospital equipment, safe and potable water, and adequate sanitation.

## States Parties' Obligations

States have several different obligations and different levels of obligations under the right to health.

### ***Immediate Obligation: Non-discrimination***

States are immediately obligated, upon ratifying the ICESCR, to ensure non-discrimination in access to health care and the underlying determinants of health. This is an immediate obligation for all states, regardless of resources because CESCR “stresses that many measures, such as most strategies and programmes designed to eliminate health-related discrimination, can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information.”

States must prohibit discrimination in access to health care and the underlying determinants of health, as well as the means and entitlements to their procurement. CESCR also emphasizes the need for equality of access to health care and health care services. CESCR explains that discrimination is prohibited on the basis of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status.

### ***Progressive Realization***

States also have an immediate obligation to take steps towards the realization of the right to health, referred to as progressive realization. Progressive realization means that “States parties have a specific and continuing obligation to move as expeditiously and effectively as possible”<sup>3</sup> towards full realization of the right to health. CESCR recognizes that the right to health cannot be immediately achieved by many States Parties. For example, some States may have to develop health care infrastructure, train health professionals, or implement health care legal reforms. The obligation for States to progressively realize the right to health requires them to make continuing efforts to implement this right, recognizing that this is a process achieved over time.

### ***Presumption against Retrogressive Measures***

Along with the obligation of progressive realization is a presumption that States should not take any retrogressive measures. This means that once a State has taken a measure to realize the right to health, it should only expand on that measure and not take away or reduce the availability of that measure.

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<sup>3</sup> UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant)*, E/1991/23 (December 14, 1990). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

### **Minimum Core**

The right to health contains a minimum essential core of elements that all States are obligated to implement. Therefore, while States must progressively realize the right to health, they must at the same time begin by at least providing and realizing the minimum essentials. CESCR General Comment 14 provides a list of 6 core obligations States must realize:

- a) Non-discriminatory access to health facilities, goods and services
- b) Access to the minimum, nutritionally adequate and safe food
- c) Access to basic shelter, housing and sanitation, and safe and potable water
- d) Provision of essential drugs (as defined by the WHO)
- e) Equitable distribution of all health facilities, goods and services
- f) Adoption and implementation of a national public health strategy and plan of action.

### **Maximum Available Resources**

ICESCR Article 2(1) also requires each State Party to realize the Covenant rights by taking steps “to the maximum of its available resources.” If a State fails to meet the minimum core obligations and attributes this to a lack of available resources, the State Party must demonstrate that it made every effort to use all available resources in an effort to satisfy the minimum core obligations.<sup>4</sup>

### **Priority Obligations**

CESCR General Comment 14 provides a list of five priority obligations for States parties. CESCR considers these priorities, in addition to the minimum core obligations, as essential to realizing the right to health.

The five priority obligations are:

- a) Ensure reproductive, maternal and child health care
- b) Provide immunization against major infectious diseases in the community
- c) Take measures to prevent, treat and control epidemic and endemic diseases
- d) Provide education and access to information on the main health problems
- e) Provide appropriate training for health personnel, including education on health and human rights.

### **Respect, Protect, Fulfil**

The right to health, “like all human rights, imposes three levels of obligations on States parties: the obligations to respect, protect and fulfil.” CESCR provides detailed explanations of these levels of obligations and with specific examples of State obligations in CESCR General Comment. The three levels are:

*Respect:* States must refrain from interfering with the enjoyment of the right to health.

*Protect:* States must take measures to prevent third parties from interfering with the enjoyment of the right to health.

*Fulfil:* States must adopt legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health.

<sup>4</sup> UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant)*, E/1991/23 (December 14, 1990); UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

### ***Implementation at the National Level***

CESCR General Comment 14 also provides guidance on how States parties should implement the right to health at the national level.

#### *Framework Legislation*

It is recommended that States develop and adopt a national health strategy based upon the right to health which lays out a clear plan for how the State will implement the right to health. The national strategy should include the formulation of policies, identification of resources, and corresponding indicators and benchmarks.

#### *Indicators and Benchmarks*

CESCR also recommends that States utilize right to health indicators and benchmarks. Indicators are used to monitor the implementation of the right to health and compliance with the State's obligations under ICESCR Article 12. This is achieved through data collection and statistical analysis.<sup>5</sup> Benchmarks are usually developed in relation to each indicator and provide the State with specific targets that it seeks to achieve. An example is provided below:

Indicator	Proportion of births attended by a skilled health professional.
Benchmark	80% of births attended by a skilled health professional by 2015.

<sup>5</sup> For more information on indicators, please see: UN Office of the High Commissioner for Human Rights, *Human Rights Indicators: A Guide to Measurement and Implementation* (2012). <http://www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx>.



## Health and Human Rights

The Resource Guide also explores the intersection between health and other human rights, beyond the right to health. Human rights are interdependent and interrelated. As CESCR General Comment 14 states:

*The right to health is closely related to and dependent upon the realization of other human rights ... including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health.*

CESCR highlights the interdependence and interrelatedness of the right to health and other human rights. However, the field of health and human rights extends beyond the interrelatedness of human rights. From the outset, the health and human rights field sought to explore the intersection of the field of health and the field of human rights. As Jonathan Mann and colleagues explained:

*[H]ealth and human rights are both powerful, modern approaches to defining and advancing human well-being. Attention to the intersection of health and human rights may provide practical benefits to those engaged in health or human rights work, may help reorient thinking about major global health challenges, and may contribute to broadening human rights thinking and practice.<sup>6</sup>*

Many international declarations and principles based on the linkage of health and human rights are relevant to practitioners. For example, the Alma-Ata Declaration underscored the need to protect health and identified primary health care as a key to achieving health for all.<sup>7</sup> The Siracusa Principles state that when there is a conflict between human rights and public health needs, governments may infringe rights if their actions are necessary to achieve legitimate objectives, provided that those actions are the least intrusive possible, and non-discriminatory in application.<sup>8</sup> These connections between health and human rights will be explored throughout each chapter.

6 Mann J et al, "Health and Human Rights," *Health and Human Rights* 1, no. 1 (Fall 1997): 8. <http://www.hhrjournal.org/archives-pdf/4065260.pdf>.  
[bannered.pdf](#).

7 International Conference on Primary Health Care, *Declaration of Alma-Ata* (Alma-Ata, USSR, Sept 6-12, 1978). [http://www.who.int/publications/alma-ata\\_declaration\\_en.pdf](http://www.who.int/publications/alma-ata_declaration_en.pdf).

8 United Nations, Economic and Social Council, *Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4, Annex (1985). [www1.umn.edu/humanrts/instate/siracusaprinciples.html](http://www1.umn.edu/humanrts/instate/siracusaprinciples.html). See also, WHO, *Guidelines for social mobilization*; WHO, "WHO Guidance on human rights and involuntary detention for xdr-tb control", [www.who.int/tb/features\\_archive/involuntary\\_treatment/en/index.html](http://www.who.int/tb/features_archive/involuntary_treatment/en/index.html).

# WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

## What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>9</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>10</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>11</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>12</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>9</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>10</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>13</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>13</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

# USING HUMAN RIGHTS MECHANISMS FOR LITIGATION AND ADVOCACY

In addition to the human rights-based approaches listed above, health and human rights advocates may lodge complaints or file reports with regional or international human rights bodies (technically known as mechanisms). In this section we highlight two types of international human rights mechanisms: courts and human rights bodies.

**Courts:** act in a judicial capacity and issue rulings that are binding on governments.

**Human rights bodies:** examine reports submitted by governments to determine compliance with human rights obligations. In some cases they have the authority to examine individual complaints of human rights violations.

## Introductory International Law Concepts

States are only legally bound by a treaty if they are a party to that treaty. The State must have ratified or acceded to the treaty to become a party to the treaty and legally obligated to implement it. Ratification occurs when a State signs the treaty and then follows its own national requirements to become legally bound by the treaty. Signing the treaty does not oblige the State to ratify the treaty nor does it make the treaty legally binding upon the State. Accession has the same legal effect as ratification. Accession occurs without signing of the treaty but when the State follows its own national requirements to become legally bound by the treaty. Both accession and ratification create a legally binding obligation to the treaty. This section highlights how treaties are legally enforced against States who are parties to the treaty so it is important to determine whether the country you are seeking to hold accountable is a party to the treaty you are seeking to use.<sup>14</sup>

It is also important to recognize the difference between ‘hard’ and ‘soft’ law. Hard law consists of treaties that are legally binding and enforceable against a state. This includes all international or regional treaties that a State has ratified or acceded to. It also includes national law. Soft law consists of international, regional or domestic instruments that are not legally binding. Soft law can include interpretations of treaties issued by treaty bodies, resolutions and declarations, principles, or guidelines. Complaints and reports filed with human rights enforcement mechanisms must be based upon a violation of ‘hard’ law – a treaty article. Soft law is often utilized to bolster or supplement an argument by demonstrating common interpretation or customary implementation of a treaty. Soft law, however, can evolve into hard law when the consistent conduct of states conforms to the soft law, out of a sense of its own obligation. This is known in international law as ‘customary law’. The distinction between hard and soft law and defining customary law can be controversial.

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<sup>14</sup> For more introductory information on international law and treaties, see: [http://treaties.un.org/doc/source/events/2012/Press\\_kit/fact\\_sheet\\_1\\_english.pdf](http://treaties.un.org/doc/source/events/2012/Press_kit/fact_sheet_1_english.pdf). For more information on key treaty terms see: [http://treaties.un.org/Pages/Overview.aspx?path=overview/definition/page1\\_en.xml#treaties](http://treaties.un.org/Pages/Overview.aspx?path=overview/definition/page1_en.xml#treaties).

## Treaties and Corresponding Enforcement Mechanisms

Note: This list includes a small sample of the treaties and enforcement mechanisms that are commonly used to advocate for health and human rights.

International Treaty	Enforcement Mechanism + Description	Mandate
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> ) <a href="http://www2.ohchr.org/english/bodies/hrc/index.htm">www2.ohchr.org/english/bodies/hrc/index.htm</a>  UN Human Rights Treaty Body	<ol style="list-style-type: none"> <li>1. Reviews periodic reports submitted by States to monitor compliance with ICCPR. Issues recommendations to States, known as concluding observations.</li> <li>2. Examines individual complaints filed against States party to the Optional Protocol.</li> <li>3. Examines inter-State complaints.</li> <li>4. Publishes interpretation of ICCPR articles, known as General Comments.</li> </ol>
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> ) <a href="http://www2.ohchr.org/english/bodies/cescr/index.htm">http://www2.ohchr.org/english/bodies/cescr/index.htm</a>  UN Human Rights Treaty Body	<ol style="list-style-type: none"> <li>1. Reviews periodic reports submitted by States to monitor compliance with ICCPR. Issues recommendations to States, known as concluding observations.</li> <li>2. Examines individual complaints filed against States party to the Optional Protocol.</li> <li>3. Publishes interpretation of ICCPR articles, known as General Comments.</li> </ol>
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> ) <a href="http://www2.ohchr.org/english/bodies/cedaw/index.htm">http://www2.ohchr.org/english/bodies/cedaw/index.htm</a>  UN Human Rights Treaty Body	<ol style="list-style-type: none"> <li>1. Reviews periodic reports submitted by States to monitor compliance with CEDAW. Issues recommendations to States, known as concluding observations.</li> <li>2. Examines individual complaints filed against States party to the Optional Protocol.</li> <li>3. May initiate confidential inquiry into situations of grave or systematic violations of States party to the Optional Protocol.</li> <li>4. Publishes interpretation of CEDAW articles, known as general recommendations.</li> </ol>
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> ) <a href="http://www2.ohchr.org/english/bodies/cerd/index.htm">http://www2.ohchr.org/english/bodies/cerd/index.htm</a>  UN Human Rights Treaty Body	<ol style="list-style-type: none"> <li>1. Reviews periodic reports submitted by States to monitor compliance with ICERD. Issues recommendations to States, known as concluding observations.</li> <li>2. Conducts preventative measures. These are early-warning measures aimed at preventing existing situations from escalating and urgent procedures responding to problems requiring immediate attention. Issues decisions, statements or resolutions.</li> <li>3. Examines inter-State complaints.</li> <li>4. Examines individual complaints filed against States party to the Optional Protocol.</li> <li>5. Publishes interpretation of ICERD articles, known as General Comments.</li> </ol>

International Treaty	Enforcement Mechanism + Description	Mandate
Convention on the Rights of the Child (CRC)	Committee on the Rights of the Child (CRC Committee) <a href="http://www2.ohchr.org/english/bodies/crc/index.htm">http://www2.ohchr.org/english/bodies/crc/index.htm</a>  UN Human Rights Treaty Body	<ol style="list-style-type: none"> <li>1. Reviews periodic reports submitted by States to monitor compliance with CRC. Issues recommendations to States, known as concluding observations.</li> <li>2. Reviews additional reports from States party to the Optional Protocols on the involvement of children in armed conflict and on the sale of children, child prostitution and child pornography.</li> <li>3. Optional Protocol to hear individual complaints adopted in December 2011, but has not entered into force. Anticipated to do so in the near future.</li> <li>4. Publishes interpretation of CRC articles, known as General Comments.</li> </ol>

Regional Treaty	Enforcement Mechanism + Description	Mandate
African Charter on Human and Peoples' Rights (ACHPR)	African Commission on Human and Peoples' Rights (ACHPR Commission) <a href="http://www.achpr.org/">http://www.achpr.org/</a>  Regional Human Rights Treaty Body	<ol style="list-style-type: none"> <li>1. Promotion of human and peoples' rights <ol style="list-style-type: none"> <li>a. The Commission carries out sensitization, public mobilization and information dissemination through seminars, symposia, and conferences.</li> <li>b. Conducts promotional missions.</li> </ol> </li> <li>2. Protection of human and peoples' rights <ol style="list-style-type: none"> <li>a. Reviews periodic reports submitted by States to monitor compliance with the Charter. Issues recommendations to States, known as concluding observations.</li> <li>b. Receives inter-state and individual communications and issues recommendations.</li> <li>c. Has friendly settlement of dispute and urgent appeal mechanisms.</li> <li>d. Special Mechanisms in the form of Special Rapporteurs, working groups or committees that investigate and report on specific human rights issues</li> <li>e. Conducts protective missions.</li> </ol> </li> <li>3. Interpretation of the Charter <ol style="list-style-type: none"> <li>a. Interprets the provisions of the Charter upon a request by a state party, organs of the African Union or individuals. No organ of the AU has referred any case of interpretation of the Charter to the Commission.</li> <li>b. Adopts resolutions expounding on the Charter provisions. Resolutions are generally 1) thematic, 2) administrative, or 3) country specific.</li> </ol> </li> </ol>



Regional Treaty	Enforcement Mechanism + Description	Mandate
<p>African Charter on Human and Peoples' Rights (<b>ACHPR</b>) and</p> <p>The Protocol on the Establishment of an African Court on Human and Peoples' Rights</p>	<p>African Court on Human and Peoples' Rights (<b>ACHPR</b>)  <a href="http://www.african-court.org/en/">http://www.african-court.org/en/</a></p> <p>Regional Human Rights Court</p>	<ol style="list-style-type: none"> <li>Judicial body that hears cases and disputes alleging violations of the African Charter on Human and Peoples' Rights, the Protocol on the Establishment of an African Court on Human and Peoples' Rights, and any other human rights treaty ratified by the state concerned.</li> <li>The Court may also render advisory opinion on any matter within its jurisdiction. The advisory opinion of the Court may be requested by the African Union, member states of the African Union, African Union organs and any African organisation recognised by the African Union.</li> </ol>
<p>[European] Convention for the Protection of Human Rights and Fundamental Freedoms (<b>ECHR</b>)</p>	<p>European Court of Human Rights (<b>ECtHR</b>)  <a href="http://www.echr.coe.int/echr/homepage_en/">http://www.echr.coe.int/echr/homepage_en/</a></p> <p>Regional Human Rights Court</p>	<ol style="list-style-type: none"> <li>Judicial body that rules on individual or State applications alleging violations of the civil and political rights set out in the European Convention on Human Rights.</li> </ol>
<p>European Social Charter (<b>ESC</b>) [1996 Revised version]</p>	<p>European Committee of Social Rights (<b>ECSR</b>)  <a href="http://www.coe.int/t/dghl/monitoring/socialcharter/ecsr/ecsrdefault_EN.asp">http://www.coe.int/t/dghl/monitoring/socialcharter/ecsr/ecsrdefault_EN.asp</a></p> <p>Regional Human Rights Treaty Body</p>	<ol style="list-style-type: none"> <li>Reviews periodic reports submitted by States to monitor compliance with ESC and adopts conclusions.</li> <li>Examines collective complaints and adopts decisions. Only organizations that have enrolled with the ECSR are entitled to submit complaints, and these are limited to EU and national trade organizations and employers' organizations as well as NGOs.</li> </ol>
<p>American Convention on Human Rights (<b>ACHR</b>)</p>	<p>Inter-American Court of Human Rights (<b>IACtHR</b>)  <a href="http://www.corteidh.or.cr/">http://www.corteidh.or.cr/</a></p> <p>Regional Human Rights Court</p>	<ol style="list-style-type: none"> <li>Judicial body that rules on cases alleging violations of the American Convention on Human Rights. The Court receives cases only from States party to the Convention or cases referred by the Inter-American Commission on Human Rights. Also, in addition to being a State party to the Convention, States must also submit to the jurisdiction of the Court which may be done case by case or in a one-time declaration.</li> <li>The Court may also issue advisory opinions submitted by OAS agencies and States regarding the interpretation of the ACHR or other human rights treaties in the American States.</li> </ol>
<p>American Convention on Human Rights (<b>ACHR</b>)</p> <p>American Declaration of the Rights and Duties of Man (<b>ADRDM</b>)</p> <p>OAS Charter</p>	<p>Inter-American Commission of Human Rights (<b>IACHR</b>)  <a href="http://www.oas.org/en/iachr/">http://www.oas.org/en/iachr/</a></p> <p>Regional Human Rights Treaty Body</p>	<ol style="list-style-type: none"> <li>Examines petitions filed by persons, NGOs, and State parties who have formally recognized the jurisdiction of the Court. Has the authority to refer the case to the IACHR.</li> <li>Monitors the human rights situation in member States. This includes, among other activities, issuing country reports and conducting country visits.</li> <li>Issues studies or reports on thematic priority areas.</li> </ol>

# RESOURCES ON HEALTH AND HUMAN RIGHTS

A list of commonly used resources on health and human rights follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. UN Documents
  - a. General Comments and Recommendations
  - b. Special Procedures of the Human Rights Council
- D. Health and Human Rights
- E. The Right to Health
- F. Litigating the Right to Health
- G. Social Determinants of Health
- H. Health Systems
- I. Social and Economic Rights Generally
- J. Health and Development
- K. Human Rights Research Resources
- L. Human Rights Case Law Research Resources
- M. Periodicals
- N. Websites

## A. International Instruments

### *Binding*

- International Labour Organization, *Convention Concerning Indigenous and Tribal Peoples in Independent Countries*, Convention No. 169 (June 27, 1989). [http://www.ilo.org/dyn/normlex/en/f?p=1000:12100:0::NO::P12100\\_ILO\\_CODE:C169](http://www.ilo.org/dyn/normlex/en/f?p=1000:12100:0::NO::P12100_ILO_CODE:C169)
- UN General Assembly, *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, Resolution 39/46, A/RES/39/46 (December 10, 1984). <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx>.
- UN General Assembly, *Convention on the Elimination of all Forms of Discrimination Against Women*, Resolution 34/180, A/RES/34/180 (December 18, 1979). <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CEDAW.aspx>.
- UN General Assembly, *Convention on the Rights of the Child*, Resolution 44/25, A/RES/44/25 (November 20, 1989). <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>.
- UN General Assembly, *Convention on the Rights of Persons with Disabilities*, Resolution 61/106, A/RES/61/106 (December 13, 2006). <http://www.un.org/disabilities/convention/conventionfull.shtml>.
- UN General Assembly, *International Covenant on Civil and Political Rights*, A/RES/21/2200 (December 16, 1966). <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CCPR.aspx>.

- UN General Assembly, *International Covenant on Economic, Social, and Cultural Rights*, A/RES/21/2200 (December 16, 1966). <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>.
- UN General Assembly, *International Convention on the Elimination of all forms of Racial Discrimination*, Resolution 2106 (XX), A/RES/20/2106 (December 21, 1965). <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CERD.aspx>.

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### **Nonbinding**

- UN Economic and Social Council, *The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4 (September 28, 1984). <http://www1.umn.edu/humanrts/instreet/siracusaprinciples.html>.
- Van Boven TC, Flinterman C, and Westendorp I, eds., *The Maastricht Guidelines on Violations of Economic, Social, and Cultural Rights*, E/C.12/2000/13 (January 22-26, 1997). [http://www.unhchr.ch/tbs/doc.nsf/o/6b748989d76d2bb8c125699700500e17/\\$FILE/G0044704.pdf](http://www.unhchr.ch/tbs/doc.nsf/o/6b748989d76d2bb8c125699700500e17/$FILE/G0044704.pdf).
- World Health Organization, *Declaration of Alma-Ata* (September 6-12, 1978). [www.who.int/publications/almaata\\_declaration\\_en.pdf](http://www.who.int/publications/almaata_declaration_en.pdf).

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## **B. Regional Instruments**

### **Binding**

- African Commission on Human and Peoples' Rights, *African Charter on the Rights and Welfare of the Child* (July 1, 1990). <http://www.achpr.org/instruments/child/>.
- African Commission on Human and Peoples' Rights, *Protocol to the African Charter on Human and Peoples' Rights: Establishment of the African Court on Human and Peoples' Rights* (June 10, 1998). <http://www.achpr.org/instruments/court-establishment/>.
- African Commission on Human and Peoples' Rights, *Protocol to the African Charter on Human and Peoples' Rights: Rights of Women in Africa* (November 7, 2003). <http://www.achpr.org/instruments/women-protocol/>.
- Council of Europe, *Convention for the Protection of Human Rights and Fundamental Freedoms*. <http://www.conventions.coe.int/Treaty/en/Treaties/Html/005.htm>.
- Council of Europe, *European Social Charter* (1996 revised edition). <http://www.conventions.coe.int/Treaty/EN/Treaties/Html/035.htm>.
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- Organization of American States: Department of International Law, *American Convention on Human Rights: 'Pact of San Jose, Costa Rica.'* [http://www.oas.org/dil/treaties\\_B-32\\_American\\_Convention\\_on\\_Human\\_Rights.htm](http://www.oas.org/dil/treaties_B-32_American_Convention_on_Human_Rights.htm).
- Organization of American States: Department of International Law, *Charter of the Organization of American States* (1948). [http://www.oas.org/dil/treaties\\_A-41\\_Charter\\_of\\_the\\_Organization\\_of\\_American\\_States.htm](http://www.oas.org/dil/treaties_A-41_Charter_of_the_Organization_of_American_States.htm).

## C. UN Documents

### a. General Comments and Recommendations

- Committee on Economic, Social, and Cultural Rights, *General Comments*. <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.
  - *General Comment 14: The right to the highest attainable standard of health*, E/C.12/2000/4 (August 11, 2000).
- Committee on the Elimination of Discrimination against Women, *General Recommendations*. <http://www2.ohchr.org/english/bodies/cedaw/comments.htm>.
  - *General Recommendation 14: Female Circumcision* (ninth session, 1990).
  - *General Recommendation 15: Women and AIDS* (ninth session, 1990).
  - *General Recommendation 18: Disabled Women* (tenth session, 1991).
  - *General Recommendation 24: Women and Health* (twentieth session, 1999).
- Committee on the Rights of the Child, *General Comments*. <http://www2.ohchr.org/english/bodies/crc/comments.htm>.
  - *General Comment 3: HIV/AIDS and the Rights of the Child*, CRC/GC/2003/3 (2003).
  - *General Comment No. 4: Adolescent health and development in the context of the Convention on the Rights of the Child*, CRC/GC/2003/4 (2004).
  - *General Comment No. 5: General Measures of Implementation of the Convention on the Rights of the Child*, CRC/GC/2003/5 (2003).
  - *General Comment No. 7: Implementing Child Rights in Early Childhood*, CRC/C/GC/7/Rev.1 (2006).
  - *General Comment No. 8: The right of the child to protection from corporal punishment and other cruel or degrading forms of punishment*, CRC/C/GC/8 (2006).
  - *General Comment 9: The Rights of Child with Disabilities*, CRC/C/GC/9 (2006).
  - *General Comment 11: Indigenous children and their rights under the Convention*, CRC/C/GC/11 (2009).
  - *General Comment No. 12: The right of the child to be heard*, CRC/C/GC/12 (2009).
  - *General Comment No. 13: The right of the child to freedom from all forms of violence*, CRC/C/GC/13 (2011).
- Committee on the Elimination of Racial Discrimination, *General Recommendations*. <http://www2.ohchr.org/english/bodies/cerd/comments.htm>.
- Committee against Torture, *General Comments*. <http://www2.ohchr.org/english/bodies/cat/comments.htm>.

**b. Special Procedures of the Human Rights Council<sup>15</sup>**

- Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, *Annual Reports*. <http://www.ohchr.org/EN/Issues/Health/Pages/Annual-Reports.aspx>.
  - *Report to the General Assembly* (main focus: right to health indicators), A/58/427 (2003).
  - *Report to the Commission on Human Rights* (main focus: definition of the human right to health), E/CN.4/2003/58 (2003).
  - *Report to the Commission on Human Rights* (main focus: sexual and reproductive health), E/CN.4/2004/49 (2004).
  - *Report to the General Assembly* (main focus: health professionals and human rights education), A/60/348 (2005).
  - *Report to the Commission on Human Rights* (main focus: mental disability), E/CN.4/2005/51 (2005).
  - *Report to the General Assembly* (main focus: the reduction of maternal mortality), A/61/338 (2006).
  - *Report to the Commission on Human Rights* (main focus: a human rights-based approach to health indicators), E/CN.4/2006/48 (2006).
  - *Report to the General Assembly* (main focus: water and sanitation), A/62/214 (2007).
  - *Report to the Human Rights Council* (main focus: the health and human rights movement), A/HRC/4/28 (2007).
  - *Report the Human Rights Council* (main focus: health systems), A/HRC/7/11 (2008).
  - *Report the Human Rights Council* (main focus: access to medicines and intellectual property rights), A/HRC/11/12 (2009).
  - *Report to the General Assembly* (main focus: informed consent), A/64/272 (2009).
  - *Report the Human Rights Council* (main focus: criminalization of same-sex conduct and sexual orientation, sex-work and HIV transmission), A/HRC/14/20 (2010).
  - *Report to the General Assembly* (main focus: harm reduction), A/65/255 (2010).
  - *Report to the General Assembly* (main focus: criminalisation of sexual and reproductive health), A/66/254 (2011).
  - *Report to the Human Rights Council* (main focus: older persons), A/HRC/18/37 (2011).
  - *Report to the Human Rights Council* (main focus: report on expert consultation on access to medicines), A/HRC/17/43 (2011).
  - *Report to the Human Rights Council* (main focus: development), A/HRC/17/25 (2011).

<sup>15</sup> The Commission on Human Rights was terminated in March 2006 and was replaced by the Human Rights Council in March 2006.

- Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, *Annual Reports*. [http://ap.ohchr.org/documents/dpage\\_e.aspx?m=103](http://ap.ohchr.org/documents/dpage_e.aspx?m=103).
  - Report to the Human Rights Council, H/HRC/22/53 (2013).
  - Report to the General Assembly, A/63/175 (2008).
- Special Rapporteur on the human rights of migrants, *Annual Reports*. <http://www.ohchr.org/EN/Issues/Migration/SRMigrants/Pages/AnnualReports.aspx>.
  - *Report to the Human Rights Council* (main focus: recapitulation of the main thematic issues, including the right to health of migrants), A/HRC/17/33 (March 21, 2011).
  - *Report to the Human Rights Council* (main focus: enjoyment of the rights to health and adequate housing by migrants), A/HRC/14/30 (April 16, 2010).
- Special Rapporteur on the right to education, *Annual Reports*. <http://www.ohchr.org/EN/Issues/Education/SREducation/Pages/AnnualReports.aspx>.
  - *Report to the UN General Assembly* (main focus: sexual education), A/65/162 (July 23, 2010).
- Special Rapporteur on violence against women, its causes and consequences, *Annual Reports*. <http://www.ohchr.org/EN/Issues/Women/SRWomen/Pages/AnnualReports.aspx>
  - *Report to the UN General Assembly* (main focus: violence against women with disabilities), A/67/227 (August 3, 2012).

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## D. Health and Human Rights

- Farmer P. *Pathologies of Power. Health, Human Rights, and the War on the Poor* (Berkeley: University of California Press, 2005).
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- Yamin A, “Shades of dignity: Exploring the demands of equality in applying human rights frameworks to health,” *Health and Human Rights* 11, no. 2 (2009). <http://www.hhrjournal.org/index.php/hhr/article/view/169/263>.
- Yamin A, “Suffering and powerlessness: The significance of promoting participation in rights-based approaches to health,” *Health and Human Rights* 11, no. 1 (2009). [www.hhrjournal.org/index.php/hhr/article/view/127/200](http://www.hhrjournal.org/index.php/hhr/article/view/127/200).
- Yamin A, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008). <http://hhrjournal.org/index.php/hhr/article/view/27/89>.

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## E. The Right to Health

- Amnesty International (Netherlands), Haki Zetu ESC Rights in Practice: The Right to Health (Amnesty International, 2012). [https://www.amnesty.nl/sites/default/files/public/the\\_right\\_to\\_adequate\\_health\\_english\\_light.pdf](https://www.amnesty.nl/sites/default/files/public/the_right_to_adequate_health_english_light.pdf).
- BMA and the Commonwealth Medical Trust, *The Right to Health: A toolkit for health professionals* (June 2007). <http://www.ifnhro.org/our-work/our-publications/353-the-right-to-health-a-toolkit-for-health-professionals-2007>.
- Clapham A and Robinson M, eds., *Swiss Human Rights Book Vol. 3: Realizing the Right to Health* (Zurich, Rüffer & Rub, 2009). [http://www.swisshumanrightsbook.com/SHRB/shrb\\_o3.html](http://www.swisshumanrightsbook.com/SHRB/shrb_o3.html). (Open access). 39 chapters available for download including:
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# GLOSSARY

## A

### Accession

An act by which a State accepts to become a State Party to a treaty and to be legally bound by it. Accession occurs when a State follows its own national requirements to become legally bound by a treaty. Accession does not require the State to sign the treaty. Accession has the same legal effect as ratification.

### Adoption

The formal act by which a treaty text is finalized and opened for accession or ratification by potential state parties.

### Amicus curiae (friend of the court)

A person, who is not a party to a lawsuit and who, on their own volition, petitions the court to file a legal document (sometimes referred to as an amicus brief) advocating a particular legal position or interpretation.

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## C

### Concluding observations

Recommendations by a treaty's enforcement mechanism on the actions a state should take to ensure compliance with the treaty's obligations. This generally follows both submission of a state's **country report** and a constructive dialogue between the treaty body and state representatives presenting the country report.

### Country report

States are obligated to submit periodic national reports on measures they have taken to comply with their treaty obligations (for treaties they have ratified or acceded to). All States, regardless of how many treaties they have ratified or acceded to, must submit a periodic report to the Universal Periodic Review.

### Customary international law

A source of international law derived from the consistent conduct of states acting out of the sense of a legal obligation. Customary law is established by showing 1) state practice and 2) opinion juris – the State's sense of legal obligation or what the State has accepted as law.

One category of customary international law is **jus cogens**. This refers to a set of principles that are so fundamental that they are non-derogable and override all conflicting international and national law. Examples of jus cogens principles include the prohibition of genocide, crimes against humanity, slave trade and human trafficking.

---

## E

### Entry into force

The date on which a treaty comes into effect and becomes legally binding. Frequently, the treaty itself specifies when the treaty enters into force, which is most often upon ratification or accession of the treaty by a specific number of States. A treaty does not enter into force on the date it is adopted.

### **Essential medicines**

“Essential medicines are those that satisfy the priority health care needs of the population ... Essential medicines are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and the community can afford.”<sup>16</sup>

### **Exhaustion of domestic remedies**

Requirement of admissibility to most international and regional courts. Before filing a complaint or case to an international or regional court, the complainant is required to pursue all available avenues for national redress unless national remedies are unreasonably delayed or unlikely to bring effective relief.

---

## **G**

### **General comments / General recommendations**

General comments or general recommendations are issued by UN treaty bodies. They provide authoritative guidance on how States Parties are expected to implement their treaty obligations. General Comments are not legally binding on States Parties, but they have significant weight as *soft law*.

---

## **H**

### **Hard Law**

Hard law consists of treaties that are legally binding and enforceable. This includes all international or regional treaties that a State has ratified or acceded to. It also includes national law.

### **Health**

A state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity (WHO).

### **Human rights**

“Universal human rights are often expressed and guaranteed by law, in the forms of treaties, customary international law, general principles and other sources of international law. International human rights law lays down obligations of Governments to act in certain ways or to refrain from certain acts, in order to promote and protect human rights and fundamental freedoms of individuals or groups.”<sup>17</sup>

### **Human rights indicators**

Indicators are used to monitor the implementation of human rights and a State’s compliance with treaty obligations. This is commonly achieved through data collection and statistical analysis.<sup>18</sup>

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<sup>16</sup> WHO, “Essential Medicines.” [http://www.who.int/topics/essential\\_medicines/en/](http://www.who.int/topics/essential_medicines/en/).

<sup>17</sup> United Nations Office of the High Commissioner for Human Rights, “What are Human Rights?” <http://www.ohchr.org/en/issues/Pages/WhatareHumanRights.aspx>.

<sup>18</sup> For more information on indicators, please see: UN Office of the High Commissioner for Human Rights, *Human Rights Indicators: A Guide to Measurement and Implementation* (2012). <http://www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx>.

## I

### **Interdependent / Interrelated / Indivisible**

Terms used to describe the relationship between human rights. They generally mean that the enjoyment of any right requires the enjoyment of other rights. The OHCHR explains that “[t]he improvement of one right facilitates advancement of the others. Likewise, the deprivation of one right adversely affects the others.”<sup>19</sup>

### **International law**

The set of rules and legal instruments regarded and accepted as binding agreements between nations. Sources of international law include: treaties, custom, general principles of law, and judicial decisions and juristic writings (Statute of the International Court of Justice, art. 38(1)(d)).

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## M

### **Maximum available resources**

Key provision of the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 2(1) obliging governments to devote the maximum of available government resources to realizing economic, social and cultural rights.

### **Monitoring/ fact finding/ investigation**

Terms often used interchangeably that are generally intended to mean the collection and analysis of information about government practices and whether there is compliance or violations of human rights.

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## N

### **Non-Discrimination**

Non-discrimination is a cross-cutting principle in international human rights law. Everyone is entitled to all human rights without distinction of any kind. The list of categories for non-discrimination is non-exhaustive and includes on the basis of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status.

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## O

### **Optional Protocol**

An optional protocol is supplemental to another treaty and establishes additional rights and obligations to that treaty. Optional protocols are subject to independent ratification.

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## P

### **Progressive realization**

Requirement that governments advance as expeditiously and effectively as possible toward the goal of realizing economic, social and cultural rights, and refrain from regressive developments.

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<sup>19</sup> UN Office of the High Commissioner for Human Rights, “What are Human Rights?” <http://www.ohchr.org/en/issues/Pages/WhatareHumanRights.aspx>

**Protocol**

The term can be used interchangeably with treaty, declaration, covenant or convention. See also “optional protocol.”

**Public health**

“Public health refers to all organized measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole. Its activities aim to provide conditions in which people can be healthy and focus on entire populations, not on individual patients or diseases. Thus, public health is concerned with the total system and not only the eradication of a particular disease.”<sup>20</sup>

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**R****Ratification**

Ratification occurs when a State signs a treaty and then fulfills its own national requirements to become legally bound by the treaty. Upon ratification, a State becomes a State Party to the treaty and is legally bound by it.

**Reservation**

A unilateral statement by a State signing, acceding to or ratifying a treaty that purports to exclude or modify the effect of certain treaty provisions. Under the Vienna Convention on the Law of Treaties, a state cannot enter a reservation that is “incompatible with the object and purpose of the treaty.”

**Right to health**

The right to the enjoyment of the highest attainable standard of mental and physical health.

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**S****Shadow report**

A supplemental report submitted to a human rights treaty body by any organisation other than the State during the periodic State reporting period. These reports allow NGOs to submit additional or alternative information to the treaty body to help the treaty body assess the state’s compliance with that treaty.

**Signature**

Signing a treaty is an expression of a state’s willingness to continue the treaty-making process and proceed to ratification. Although the provisions of the treaty are not legally binding upon signature, it does create an obligation for that State to refrain in good faith from acts that would defeat the object and purpose of the treaty.

**Soft Law**

Soft law consists of international, regional or domestic instruments that are not legally binding. Soft law can include interpretations of treaties issued by treaty bodies, resolutions and declarations, principles, or guidelines. Soft law is often utilized to bolster or supplement arguments by demonstrating common interpretation or customary implementation of a treaty.

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<sup>20</sup> World Health Organization, “Public Health.” <http://www.who.int/trade/glossary/story076/en/>.

### **Special procedures**

Activities covered by the mandate of the Human Rights Council to address thematic or country-specific human rights issues. Special procedures include individuals named as *special rapporteur*, independent expert, special representative of the Secretary-General, and *working groups*.<sup>21</sup>

### **Special rapporteurs**

Independent human rights experts appointed by the Human Rights Council to report and advise on human rights from a thematic or country-specific perspective. Their mandate authorizes them to undertake country visits, send communications to States with alleged violations of human rights, conduct studies, report annually to the Human Rights Council, and, for most mandates, report to the General Assembly.

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## **T**

### **Treaty**

“A ‘treaty’ is a formally concluded and ratified agreement between States. The term is used generically to refer to instruments binding at international law, concluded between international entities (States or organizations). Under the Vienna Conventions on the Law of Treaties, a treaty must be (1) a binding instrument, which means that the contracting parties intended to create legal rights and duties; (2) concluded by states or international organizations with treaty-making power; (3) governed by international law and (4) in writing.”<sup>22</sup>

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## **U**

### **Underlying determinants of health**

Factors that promote conditions in which people can live a healthy life. The underlying determinants of health include an adequate supply of safe food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.

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## **W**

### **Working groups**

Small committees, usually composed of five independent experts, appointed by the Human Rights Council to conduct research on a particular human rights issue.

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<sup>21</sup> For more information see: ESCR-Net, *Manual on the Special Procedures of the Human Rights Council* (June 2006). <http://www.escr-net.org/docs/i/425392>.

<sup>22</sup> UNICEF, *Introduction to the Convention on the Rights of the Child: Definition of Key Terms*. <http://www.unicef.org/crc/files/Definitions.pdf>.



# CHAPTER I



## PATIENT CARE AND HUMAN RIGHTS

“ If further progress is to be made towards the operationalization of the right to health, many more health professionals must begin to appreciate the human rights dimensions of their work. ”

— Paul Hunt, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/4/28 - January 17, 2007

## **Health and Human Rights Resource Guide**

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# INTRODUCTION

This chapter will introduce you to key issues and resources related to human rights in patient care, with a particular focus on issues such as access to information and care, consent, and confidentiality.

While other chapters in this Resource Guide focus on specific populations—such as people living with and affected by HIV, people who use drugs, LGBTI communities, and minority and indigenous communities—this chapter addresses human rights issues affecting patients as a whole.

The chapter is organized into six sections that answer the following questions:

1. How is patient care a human rights issue?
2. What are the most relevant international and regional human rights standards related to patient care?
3. What is a human rights-based approach to advocacy, litigation, and programming?
4. What are some examples of effective human rights-based work in the area of patient care?
5. Where can I find additional resources on human rights in patient care?
6. What are key terms related to human rights in patient care?

# I. HOW IS PATIENT CARE A HUMAN RIGHTS ISSUE?

## What is patient care?

Patient care refers to the prevention, treatment, and management of illness and the preservation of physical and mental well-being through services offered by health professionals.<sup>1</sup> Patient care consists of services rendered by health professionals (or non-professionals under their supervision) for the benefit of patients.<sup>2</sup> A patient is a user of health care services whether he or she is healthy or sick.<sup>3</sup>

## What are the issues and how are they human rights issues?

Patients are entitled to the full range of human rights. Health care providers must respect each patient's dignity and autonomy, right to participate in making health care decisions, right to informed consent, right to refuse medical treatment, and right to confidentiality and privacy. The attention, treatment, and care that each health care provider gives to a patient must respect the human rights of every one of his or her patients.

The human rights-based approach to patient care draws from standards contained in the international human rights framework, which are often mirrored in regional treaties and national constitutions. It differs from patients' rights, which codify particular rights that are relevant only to patients. Human rights standards apply to all stakeholders in the delivery of health care—including both patients and care providers.

A human rights-based approach seeks, above all, to uphold the inherent human dignity of all actors in the care provider-patient relationship. This relationship can be a complex one, especially when coupled with health care delivery. For example, as medicine becomes ever more advanced, providers and patients must work together to make diagnostic and therapeutic decisions.<sup>4</sup> Financial and quality issues are always present in health care delivery and can lead to inequality and discrimination.<sup>5</sup> Greater understanding is needed of the social determinants of health that straddle the lines between traditional medicine and a broader concept of health, as well as of the interdependence of the right to health and the realization of all human rights.<sup>6</sup> A human rights-based approach uses the human rights framework to analyze these elements of patient care, among others.

Below are some common human rights issues that arise in patient care settings. This list is not comprehensive. The list alternates between highlighting issue areas and highlighting marginalized groups whose human rights are frequently violated in the health care setting.

<sup>1</sup> Dorland's Illustrated Medical Dictionary, 28th ed., p. 269.

<sup>2</sup> This definition, and other similar definitions, are often provided for the term "health care."

<sup>3</sup> World Health Organization (WHO), *Declaration on the Promotion of Patients' Rights in Europe, European Consultation on the Rights of Patients*, (1994).

<sup>4</sup> Leaning J, "Human rights and medical education," *Boston Medical Journal* 315 (1997): 1390. <http://dx.doi.org/10.1136/bmj.315.7120.1390>.

<sup>5</sup> Ibid.

<sup>6</sup> Ibid.

## Right to information

Patients are often unaware of their rights, including the right to information on their condition and the right to access their medical records. In a study conducted at four hospitals in Lithuania, 85% of the staff and 56% of the patients surveyed had heard of or read about patients' rights laws.<sup>7</sup> Moreover, only 50% of professionals and 69% of patients thought it was necessary for patients to have information about diagnosis, treatment results, and alternative modes of treatment.<sup>8</sup> Another study in Macedonia found that 82% of respondents stated that there are patient rights, but 56% did not know what their rights were.<sup>9</sup>

Patients have the right to information about their health status, treatment options and reasonable alternatives, and the likely benefits and risks of proposed treatment and non-treatment. Patients also have the right to access their medical chart and medical history.

## Right to privacy and confidentiality

Patients have the right to have their health information and data kept confidential. According to Gostin et al., "Health data may include not only a patient's sensitive health status, but also those facts or circumstances that the patient reveals to [health care workers] as part of seeking medical treatment."<sup>10</sup> The "right to privacy and confidentiality must be applied sensitively, with respect for different cultural, social, and religious traditions."<sup>11</sup>

For certain vulnerable groups, the right to privacy and confidentiality is an essential aspect of obtaining health care. For example, privacy and confidentiality are crucial to realizing sexual and reproductive rights for women and adolescents.<sup>12</sup> In General Comment 14 on the right to health, the Committee on Economic, Social and Cultural Rights states that "[t]he realization of the right to health of adolescents is dependent on the development of youth-friendly health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services."<sup>13</sup>

Privacy and confidentiality are also crucial for patients seeking diagnosis and treatment of illnesses with which stigma is attached, such as HIV/AIDS and mental illness. Depending on the type of care an individual is seeking, some health care centers may only allow specific providers to access the patient's health information. For example, a nurse who is vaccinating a patient may not access that individual's private mental health records because the information is not relevant to the treatment being provided at that current moment.

The right to confidentiality of health information should not interfere with the right to access of private health information. While a holder of private health information should be prohibited from sharing that information with anyone who is not essential to providing health care to the individual, the holder must provide the individual access to their private health information upon the individual's request. Patients have the right to access their own health information, to be able to control how the information is shared with them (for example, being able to indicate to where mail or phone calls are directed), and to be able to authorize the disclosure of information when desired. The right to confidentiality of private health informa-

7 Ducinskiene D et al, "Awareness and practice of patient's rights law in Lithuania," *BMC International Health and Human Rights* 6 (2006):10. [www.biomedcentral.com/1472-698X/6/10](http://www.biomedcentral.com/1472-698X/6/10).

8 Ibid.

9 Velik-Stefanovska V et al, "Rights of Patients in Macedonia According to European Standards" (2005).

10 Gostin L et al, *The Domains of Health Responsiveness – A Human Rights Analysis* (World Health Organization Health and Human Rights Working Paper Series No 2, 2003). [www.who.int/hhr/information/en/Series\\_2%20Domains%20of%20health%20responsiveness.pdf](http://www.who.int/hhr/information/en/Series_2%20Domains%20of%20health%20responsiveness.pdf).

11 Ibid.

12 Inter-American Commission on Human Rights (IACHR), *Access to Information on Reproductive Health from a Human Rights Perspective* (Nov. 11, 2011). [www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf](http://www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf).

13 UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000).

tion, as well as the right to accessibility of private health information, should be upheld and not compromised in respecting the rights of the patient.

## Right to informed consent to treatment

The UN Special Rapporteur on the right to health, Anand Grover, defines informed consent as the following:

*Informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers. Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well-being.*<sup>14</sup>

The right to informed consent is central to the right to health. Issues that arise concern the competency or legal capacity of the patient to consent, respect for personal autonomy, the sufficiency and completeness of information, and circumstances compelling limits on the need for informed consent.

The complexity of informed consent is mirrored by patients' lack of understanding of its meaning and importance. For example, in a 2006 study of 732 European surgical patients in obstetrics and gynecology during a six-month period, about 46% believed that the primary function of the written consent form was to protect the hospital, and 68% thought that the form allowed doctors to take control, while only 41% believed consent forms expressed their own wishes for treatment.<sup>15</sup>

Derogations, or departures, from the right to informed consent are necessary at times, but the question of when derogations may be permitted is a complicated one. When a patient is unconscious, medical providers must seek consent from a legally entitled representative. However, if there is an emergency situation where the patient's life is in danger, medical providers may presume that consent is given. Issues of informed consent also arise from public health policies that require compulsory testing, compulsory vaccinations, or mandated quarantine during epidemics. Procedural safeguards are crucial to derogations from informed consent, to ensure that proper circumstances are met and to provide a means to challenge the departure from the law. Some groups are particularly vulnerable to violations of the right to informed consent. The UN Special Rapporteur on the right to health brought attention to children, elderly persons, women, ethnic minorities, indigenous peoples, persons with disabilities, persons living with HIV/AIDS, persons deprived of liberty, sex workers, and persons who use drugs.<sup>16</sup>

The Inter-American Court points out the issues surrounding free and voluntary consent when it comes to women's sexual and reproductive rights.<sup>17</sup> Access to information on sexual and reproductive health is crucial for women to make free and informed decisions. According to the Inter-American system, access to information on sexual and reproductive health "involves a series of rights such as the right to freedom of expression, to personal integrity, to the protection of the family, to privacy, and to be free from violence and discrimination."<sup>18</sup>

<sup>14</sup> UN General Assembly, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (Aug. 10, 2009).

<sup>15</sup> Akkad A et al, "Patients' perceptions of written consent: questionnaire study," *Boston Medical Journal* 333(2006):528. [www.bmj.com/content/333/7567/528](http://www.bmj.com/content/333/7567/528).

<sup>16</sup> UN General Assembly, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (Aug. 10, 2009).

<sup>17</sup> Inter-American Commission on Human Rights, *Access to Information on Reproductive Health from a Human Rights Perspective* (Nov. 11, 2011). [www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf](http://www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf).

<sup>18</sup> *Ibid.*



There is also particular concern and confusion regarding the right to informed consent for persons with disabilities or mental health illness, two groups whose rights are frequently violated. Treatment decisions are often based on inappropriate factors such as ignorance or stigma surrounding disabilities, and indifference or expediency from staff. The Special Rapporteur on the right to health writes, “[These inappropriate considerations are] inherently incompatible with the right to health, [and] the prohibition of discrimination on the ground of disability ... In these circumstances, it is especially important that the procedural safeguards protecting the right to informed consent are both watertight and strictly applied.”<sup>19</sup> For more detailed information on disability and health, please see Chapter 9.

## Persons unable to provide informed consent

Patients may be deemed legally incompetent to make decisions on their own behalf, including providing informed consent to treatment. Patients who are declared legally incompetent can include unconscious patients; minors; patients experiencing confusion or other altered mental states (this includes the elderly); those under the influence of sedatives or other drugs that affect alertness and cognition; and on occasion, persons with disabilities, depending upon their perceived impairment.<sup>20</sup>

Many countries have a system in which a guardian or representative is authorized to make decisions on behalf of the legally incompetent individual. Depending on the jurisdiction and circumstances, health providers might also have the authority to commit a person involuntarily to a health care facility. Involuntary commitment is generally reserved for severe cases where the person is in immediate danger of harming him/herself or others.

There are frequent issues with guardianship and involuntary commitment because these processes involve denying an individual their autonomy to make decisions. It is crucial that the system be as formal and transparent as possible and to establish procedural safeguards to ensure that the dignity and rights of the individual are upheld. An example of a procedural safeguard for involuntary commitment is to allow courts or tribunals access to challenge the admission.<sup>21</sup> For more information, please see Chapter 9 on Disability.

## Prisoners

Prisoners who are ill often face violations of their rights as patients. Prisoners have the same rights as other patients, including the right to refuse treatment, the right to informed consent, the right to privacy and confidentiality, and the right to information. For example, they have the right to refuse treatment, including abortions and medical testing.<sup>22</sup> Conducting these procedures without informed consent would be coerced or forced and in violation of the prisoner’s right to refuse treatment. Derogations from the right to refuse treatment in prison include the prevention and control of communicable diseases and the treatment of mental illness, but both are subject to specific conditions and should be implemented in line with international standards.<sup>23</sup> The prison population includes especially vulnerable groups with special needs, including prisoners with mental health care needs, elderly prisoners, and prisoners with terminal illness.<sup>24</sup> These vulnerable sub-populations may require special attention to ensure that their rights to health and life with dignity are realized.

19 UN Commission on Human Rights, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, E/CN.4/2005/51 (Feb. 11, 2005).

20 World Medical Assembly (WMA), Declaration of Lisbon on the Rights of the Patient, (1981). [www.wma.net/en/30publications/10policies/14/](http://www.wma.net/en/30publications/10policies/14/).

21 UN Commission on Human Rights, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, E/CN.4/2005/51 (Feb. 11, 2005).

22 Lines R, “The right to health of prisoners in international human rights law,” *International Journal of Prisoner Health*, 4, no. 1 (March 2008): 3-53. [www.ahrn.net/library\\_upload/uploadfile/file3102.pdf](http://www.ahrn.net/library_upload/uploadfile/file3102.pdf).

23 Ibid.

24 United Nations Office of Drugs and Crime, *Handbook on Prisoners with special needs* (2009). [www.unodc.org/documents/justice-and-prison-reform/Prisoners-with-special-needs.pdf](http://www.unodc.org/documents/justice-and-prison-reform/Prisoners-with-special-needs.pdf).



## Women

Women are particularly vulnerable to violations of their rights while seeking health care, especially for sexual and reproductive health care services. For example, Human Rights Watch documented abuse of pregnant women during health care visits in South Africa:

*[Forms of abuse] include ridiculing or ignoring women's needs when in pain, especially during labour, unnecessary delays in providing treatment, leaving women to deliver their babies without help, accusing women who appear not to be following nurses' orders of wanting to harm their babies, verbal insults and degrading treatment, such as asking women to clean up their own blood, or intimidation and threats of harm. Physical abuse involves slapping, pinching, rough treatment and a deliberate refusal to give pain-relieving medication.<sup>25</sup>*

Other issues include independent and autonomous access to sexual and reproductive services, forced sterilization and forced contraception, and physical and sexual abuse by the care giver.<sup>26</sup> Violence and assault against women in sexual and reproductive health care settings perpetuates stigma and discrimination against women that denies them human dignity.

The Special Rapporteur to health notes, “Stigma and discrimination against women from marginalized communities, including indigenous women, women with disabilities and women living with HIV/AIDS, have made women from these communities particularly vulnerable to such abuses.”<sup>27</sup> The Special Rapporteur on water explains, “Stigma is, by its demeaning and degrading nature, antithetical to the very idea of human dignity. Stigma as a process of devaluation, of making some people “lesser” and others “greater”, is inconsistent with human dignity, which is premised on notions of the inherent equality and worthiness of the human person. It undermines human dignity, thereby laying the groundwork for violations of human rights.”<sup>28</sup> Female patients from marginalized populations have the right to seek health care in a manner that is non-discriminatory and respects their dignity.

## Access to essential medicines

Access to essential medicines is lacking in many developing countries. An estimated 1.3 to 2.1 billion people worldwide have no access to essential medicines. According to a 2011 study, about one third of the world population lacks regular access to essential medicines.<sup>29</sup> Only 10% of pharmaceutical research and development spending is directed to health problems that account for 90% of the global disease burden. A small number of companies dominate global production, trade, and sale of medicines. Ten companies account for almost half of all sales.<sup>30</sup> However, “Inequity in access to essential medicines is part of inequity in health care.”<sup>31</sup> An expert consultation on access to medicines recommended in 2011 that “From the right to health perspective, access to medicines must be equitable. Additionally, more research and development is needed to promote the availability of new drugs for those diseases causing a heavy burden on developing countries.”<sup>32</sup>

25 Human Rights Watch, *Healthcare is Failing Women* (Dec. 20, 2011). [www.hrw.org/news/2011/12/20/healthcare-failing-women](http://www.hrw.org/news/2011/12/20/healthcare-failing-women).

26 Inter-American Commission on Human Rights, *Access to Information on Reproductive Health from a Human Rights Perspective* (Nov. 11, 2011). [www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf](http://www.oas.org/en/iachr/women/docs/pdf/womenaccessinformationreproductivehealth.pdf); UN General Assembly, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (Aug. 10, 2009).

27 Ibid.

28 UN Human Rights Council, *Special Rapporteur on the human right to safe drinking water and sanitation*, A/HRC/21/42 (July 2, 2012).

29 Hogerzeil H and Mirza Z, *The World Medicines Situation in 2011: Access to Essential Medicines as Part of the Right to Health* (WHO, 2011). <http://apps.who.int/medicinedocs/documents/s18772en/s18772en.pdf>.

30 World Health Organization (WHO), *The World Medicines Situation* (2004). <http://apps.who.int/medicinedocs/en/d/Js6160e/9.html>. The 2011 edition is being released chapter by chapter and will be available at: [www.who.int/medicines/areas/policy/world\\_medicines\\_situation/en/index.html](http://www.who.int/medicines/areas/policy/world_medicines_situation/en/index.html).

31 Hogerzeil H and Mirza Z, *The World Medicines Situation in 2011: Access to Essential Medicines as Part of the Right to Health* (WHO, 2011). <http://apps.who.int/medicinedocs/documents/s18772en/s18772en.pdf>.

32 UN Human Rights Council, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/17/43 (Mar. 16, 2011).

High pricing is another factor that hinders access to medicines. Companies that develop new medicines are often granted a patent, which permits that company to be the sole manufacturer of that medicine for a designated period of time. The expert consultation on access to medicines explains:

*While intellectual property rights have the important function of providing incentives for innovation, they can, in some cases, obstruct access by pushing up the price of medicines. The right to health requires a company that holds a patent on a lifesaving medicine to make use of all the arrangements at its disposal to render the medicine accessible to all.<sup>33</sup>*

Access to essential medicines is considered an integral part of the right to health. However, 60 countries do not recognize the right to health in their national constitutions and more than 30 countries have not yet ratified the International Convention on Economic, Social, and Cultural Rights. General Comment 14 says that States must make public health and health care facilities available, including “essential drugs, as defined by the WHO Action Programme on Essential Drugs.”<sup>34</sup>

## What are the current practices in the area of patient care?

Methods for applying human rights to patient care are diverse and occur on multiple levels of government and through engagement with private actors. A common approach to incorporating human rights norms into patient care is through the development of a code or declaration of patient rights. It is important to keep in mind that this approach does not cover the full range of rights and duties that should be applied to all stakeholders in health care provision. However, developing patient rights that are based upon human rights standards and principles is an important step in delineating the rights and obligations of patients in relation to their health care providers.

Bioethics is another avenue to incorporating human rights into patient care. The definition of “bioethics” remains controversial, but generally the field covers ethical issues arising in the life sciences, medicine, and technology. Bioethics often deals with moral and ethical issues of medical and scientific research as well as approaches to dealing with epidemics. Subsumed under bioethics, too, are ethical issues arising from the relationship between patient and doctor.

When evaluating codifications of patients’ rights or bioethics, it is important to understand that they may contain some human rights principles and elements, but may not necessarily contain the full range of rights granted under human rights law.

In the table below, we provide four different codifications of patients’ rights. We provide these four to offer a picture of the different approaches that can be taken to this subject. It is interesting to note the extent to which each codification incorporates human rights principles and how each codification focuses on certain sets of rights.

<sup>33</sup> Ibid.

<sup>34</sup> UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000). [www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En).

1. **Universal Declaration on Bioethics and Human Rights (UDBHR).**<sup>35</sup> The UDBHR was adopted by UNESCO's General Conference on October 19, 2005. The declaration was developed by the International Bioethics Committee under UNESCO, which "follows progress in the life sciences and its applications in order to ensure respect for human dignity and freedom."<sup>36</sup>
2. **Declaration of Lisbon.**<sup>37</sup> The World Medical Association's Declaration of Lisbon on the Rights of the Patient was created in 1981. This declaration was not created using the human rights framework. The preamble states:

*While a physician should always act according to his/her conscience, and always in the best interests of the patient, equal effort must be made to guarantee patient autonomy and justice. The following Declaration represents some of the principal rights of the patient that the medical profession endorses and promotes.*<sup>38</sup>

This statement expressly recognizes the rights of physicians to act according to their best medical knowledge. To this end, it is the only declaration in the table below that incorporates a provision on procedures against the patient's will.

3. **European Convention on Human Rights and Biomedicine.**<sup>39</sup> The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine was adopted by the Council of Europe in 1997. This convention sets out certain basic patient rights principles, such as equitable access to health care and protection of consent, private life, and right to information.
4. **European Charter of Patients' Rights (ECPR).**<sup>40</sup> The ECPR was compiled in 2002 by Active Citizenship Network, a European network of civic, consumer, and patient organizations. This charter was part of a grassroots movement across Europe for patients to play a more active role in shaping the delivery of health services and an attempt to translate regional documents on the right to health care into specific provisions.<sup>41</sup> Although this charter is not legally binding, a strong network of patient rights groups across Europe has successfully lobbied their national governments for recognition and adoption of rights in the charter.<sup>42</sup> The charter has also been used as a reference point to monitor and evaluate health care systems across Europe. In September 2007, the European Economic and Social Committee (EESC) approved its own initiative opinion on patients' rights, declaring that it "welcomes and acknowledges" the European Charter of Patients' Rights.

35 United Nations Educational, Scientific and Cultural Organization (UNESCO), Universal Declaration of Bioethics and Human Rights, 2005. [www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/](http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/).

36 United Nations Educational, Scientific and Cultural Organization (UNESCO), "International Bioethics Committee," [www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/international-bioethics-committee/](http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/international-bioethics-committee/).

37 World Medical Assembly, Declaration of Lisbon on the Rights of the Patient [Declaration of Lisbon], 1981. [www.wma.net/en/30publications/10policies/14/](http://www.wma.net/en/30publications/10policies/14/).

38 Ibid.

39 Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine [Convention on Human Rights and Biomedicine], 1997. <http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm>.

40 Active Citizenship Network, European Charter of Patients' Rights [ECPR], 2002. [www.eesc.europa.eu/self-and-coregulation/documents/codes/private/o85-private-act.pdf](http://www.eesc.europa.eu/self-and-coregulation/documents/codes/private/o85-private-act.pdf).

41 It is important to note that the pharmaceutical company Merck & Co. also provided funding for this movement.

42 One of the activities of new EU member-states during the process of preparation for accession in the EU was adjustment of health care legislation towards European standards. Many countries, such as Bulgaria, adopted a new health law, whose structure and contents are strictly in line with the European Charter of Patients' Rights.

**Table: Codifications of patients' rights**

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
<b>Protection of Human Dignity</b>	<p><b>Article 3 – Human dignity and human rights</b></p> <p>1. Human dignity, human rights and fundamental freedoms are to be fully respected.</p> <p><b>Article 10 – Equality, justice and equity</b></p> <p>The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.</p>	<p><b>10. Right to dignity</b></p> <p>a. The patient's dignity and right to privacy shall be respected at all times in medical care and teaching, as shall his/her culture and values.</p>	<p><b>Article 1 – Purpose and object</b></p> <p>Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.</p>	
<b>Non-Discrimination</b>	<p><b>Article 11 – Non-discrimination and non-stigmatization</b></p> <p>No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.</p>	<p><b>1. Right to medical care of good quality</b></p> <p>a. Every person is entitled without discrimination to appropriate medical care.</p>	<p><b>Article 11 – Non-discrimination</b></p> <p>Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.</p>	<p><b>2 - Right of access</b></p> <p>The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services.</p>
<b>Primacy of the Patient</b>	<p><b>Article 3 – Human dignity and human rights</b></p> <p>2. The interests and welfare of the individual should have priority over the sole interest of science or society.</p>	<p><b>1. Right to medical care of good quality</b></p> <p>c. The patient shall always be treated in accordance with his/her best interests.</p>	<p><b>Article 2 – Primacy of the human being</b></p> <p>The interests and welfare of the human being shall prevail over the sole interest of society or science.</p>	
<b>Access to Health Care</b>	<p><b>Article 14 – Social responsibility and health</b></p> <p>2. ... progress in science and technology should advance:</p> <p>(a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good.</p>		<p><b>Article 3 – Equitable access to health care</b></p> <p>Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.</p>	<p><b>2 - Right of access</b></p> <p>Every individual has the right of access to the health services that his or her health needs require. ...</p>

**Table: Codifications of patients' rights (cont.)**

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
<b>Quality of Care</b>		<p><b>1. Right to medical care of good quality</b></p> <p>c. ... The treatment applied shall be in accordance with generally approved medical principles.</p> <p>d. Quality assurance should always be a part of health care. Physicians, in particular, should accept responsibility for being guardians of the quality of medical services.</p>	<p><b>Article 4 – Professional standards</b></p> <p>Any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards.</p>	<p><b>8 - Right to the Observance of quality standards</b></p> <p>Each individual has the right of access to high quality health services on the basis of the specification and observance of precise standards. The right to quality health services requires that health care institutions and professionals provide satisfactory levels of technical performance, comfort and human relations ...</p>
<b>Individual Autonomy</b>	<p><b>Article 5 – Autonomy and individual responsibility</b></p> <p>The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.</p>	<p><b>3. Right to self-determination</b></p> <p>a. The patient has the right to self-determination, to make free decisions regarding himself/herself. The physician will inform the patient of the consequences of his/her decisions.</p>		<p><b>5 - Right to free choice</b></p> <p>Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information. The patient has the right to decide which diagnostic exams and therapies to undergo, and which primary care doctor, specialist or hospital to use ...</p>
<b>Information</b>		<p><b>7. Right to information</b></p> <p>a. The patient has the right to receive information about himself/herself recorded in any of his/her medical records, and to be fully informed about his/her health status including the medical facts about his/her condition. ...</p>	<p><b>Article 10 – Private life and right to information</b></p> <p>2. Everyone is entitled to know any information collected about his or her health. ...</p>	<p><b>3 - Right to information</b></p> <p>Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available. ...</p>

**Table: Codifications of patients' rights (cont.)**

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
<b>Informed Consent</b>	<p><b>Article 6 – Consent</b></p> <p>1. Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information ...</p>	<p><b>3. Right to self-determination</b></p> <p>b. A mentally competent adult patient has the right to give or withhold consent to any diagnostic procedure or therapy. The patient has the right to the information necessary to make his/her decisions...</p>	<p><b>Article 5 – General rule</b></p> <p>An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it ...</p>	<p><b>4 - Right to consent</b></p> <p>Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health; this information is a prerequisite for any procedure and treatment ...</p>
<b>Persons Who Lack Capacity to Provide Informed Consent</b>	<p><b>Article 7 – Persons without the capacity to consent</b></p> <p>In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent:</p> <p>(a) authorization for research and medical practice should be obtained in accordance with the <u>best interest of the person concerned</u> and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent; ...</p>	<p><b>4. The unconscious patient</b></p> <p>a. If the patient is unconscious or otherwise unable to express his/her will, informed consent must be obtained whenever possible, from a <u>legally entitled representative</u>. ...</p> <p><b>5. The legally incompetent patient</b></p> <p>a. If a patient is a minor or otherwise legally incompetent, the consent of a <u>legally entitled representative</u> is required in some jurisdictions. Nevertheless the patient must be involved in the decision-making to the fullest extent allowed by his/her capacity...</p>	<p><b>Article 6 – Protection of persons not able to consent</b></p> <p>1. ... an intervention may only be carried out on a person who does not have the capacity to consent, for his or her <u>direct benefit</u> ...</p> <p><b>Article 7 – Protection of persons who have a mental disorder</b></p> <p>... a person who has a mental disorder of a serious nature may be subjected, without his or her consent, to an intervention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health.</p> <p><b>Article 8 – Emergency situation</b></p> <p><b>Article 9 – Previously expressed wishes</b></p>	<p><b>4 - Right to consent</b></p> <p>In all circumstances which provide for a <u>legal representative</u> to give the informed consent, the patient, whether a minor or an adult unable to understand or to will, must still be as involved as possible in the decisions regarding him or her. The informed consent of a patient must be procured on this basis.</p>

**Table: Codifications of patients' rights (cont.)**

	UHBHR (2005)	Declaration of Lisbon (1981)	Convention on Human Rights and Biomedicine (1997)	ECPR (2002)
<b>Privacy and Confidentiality</b>	<p><b>Article 9 – Privacy and confidentiality</b></p> <p>The privacy of the persons concerned and the confidentiality of their personal information should be respected. ...</p>	<p><b>8. Right to confidentiality</b></p> <p>a. All identifiable information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death. ...</p>	<p><b>Article 10 – Private life and right to information</b></p> <p>Everyone has the right to respect for private life in relation to information about his or her health.</p>	<p><b>6-Right to privacy and confidentiality</b></p> <p>Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general. ...</p>

**The European Charter of Patients' Rights contains 14 provisions, of which only seven are featured within the table above. The full list of provisions is:**

1. Right to Preventative Measures
2. Right of Access
3. Right to Information
4. Right to Consent
5. Right to Free Choice
6. Right to Privacy and Confidentiality
7. Right to Respect Patients' Time
8. Right to the Observance of Quality Standards
9. Right to Safety
10. Right to Innovation
11. Right to Avoid Unnecessary Suffering and Pain
12. Right to Personalized Treatment
13. Right to Complain
14. Right to Compensation



## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO PATIENT CARE?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to patient care. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<p><b>UN treaty body interpretation</b></p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
<b>Human rights standards</b>	<p><b>Case law</b></p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights in patient care.



## Abbreviations

In the tables, we use the following abbreviations to refer to the eleven treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )

Also cited are the former Commission on Human Rights (CHR) and various UN Special Rapporteurs (SR) and Working Groups (WG).

## Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Liberty and Security of Person	Art. 3	Art. 9(1)			Art. 5(b)	
Privacy	Art. 12	Art. 17				Art. 16
Expression and Information	Art. 19	Art. 19(2)				Art. 13, Art. 17
Bodily Integrity						
Life	Art. 3	Art. 6(1)				Art. 6(1)
Health	Art. 25		Art. 12	Art. 12	Art. 5(e)(iv)	Art. 24
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)
Participate in Public Policy	Art. 21	Art. 25		Art. 7	Art. 5(c)	
Non-discrimination and Equality	Art. 1, 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

## Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Liberty and Security of Person	Art. 6	Art. 5(1)		Art. I	Art. 7
Privacy		Art. 8		Art. V	Art. 11
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Bodily Integrity					
Life	Art. 4	Art. 2		Art. I	Art. 4
Health	Art. 16		Art. 11 Art. 13	Art. XI	
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 3			Art. 5(2)
Participate in Public Policy	Art. 13			Art. XX	Art. 23
Non-discrimination and Equality	Art. 2 Art. 19	Art. 14	Art. E	Art. II	Art. I (I)

**Table I: Patient Care and the Right to Liberty and Security of the Person**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A hospital employs excessive restraints on patients, such as tying them to a bed or wheelchair for hours each day.</li> <li>• Mentally ill patients are confined without a set procedure or standard.</li> <li>• There are unjustified delays in reviewing whether mentally ill patients must continue to be institutionalized.</li> <li>• Patients are detained in hospitals for their inability to pay bills.</li> <li>• Patients are quarantined unnecessarily.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<b>ICCPR 9(1)</b> Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.	<b>HRC:</b> Considering a period of 14 days of detention for mental health reasons without review by a court in <b>Estonia</b> incompatible with ICCPR 9. CCPR/CO/77/EST (HRC, 2003)

Human Rights Standards	Case Law
<b>ECHR 5(1)</b> Everyone has the right to liberty and security of person. No one shall be deprived of their liberty except in accordance with a procedure prescribed by law [due process] and except in those instances specifically enumerated by this Convention (paraphrase).	<p><b>ECtHR:</b> Establishing that civil commitment must follow a procedure prescribed by law and cannot be arbitrary; the person must have a recognized mental illness and require confinement for the purposes of treatment. <i>Winterwerp v. The Netherlands</i>, 6301/73 (November 27, 1979)</p> <p><b>ECtHR:</b> Mandating speedy periodic legal review of civil commitment with the essential elements of due process. <i>X v. United Kingdom</i>, 7215/75 (November 5, 1981).</p> <p><b>ECtHR:</b> Awarding damages for violation of liberty interests to a patient detained in a Hungarian psychiatric hospital for 3 years where the judicial decision of the national court was superficial and insufficient to show dangerous conduct. <i>Gajcsi v. Hungary</i>, 34503/03 (October 3, 2003).</p> <p><b>ECtHR:</b> The applicant, who had been diagnosed with autism, was admitted to the hospital as an “informal patient” between 22 July and 29 October 1997, which he maintained amounted to a deprivation of liberty under Art. 5(1). The Court noted that there were no formalised admission procedures, and that because of the lack of procedural safeguards the hospital staff “assumed full control of the liberty and treatment of a vulnerable incapacitated individual solely on the basis of their own clinical assessments completed as and when they considered fit.” The Court held that “this absence of procedural safeguards fails to protect against arbitrary deprivations of liberty on grounds of necessity and, consequently, to comply with the essential purpose of Article 5 § 1” and therefore found a violation of Art. 5(1). <i>H.L. v. United Kingdom</i>, 45508/99 (October 5, 2004).</p> <p><b>ECtHR:</b> The applicant was admitted to a clinic for an extended stay where she attempted to escape several times. The Court stated that in order to determine whether there was a deprivation of her liberty, the starting-point had to be the specific situation of the individual concerned with account taken of a wide range of factors, such as the type, duration, effects and manner of implementation of the measure in question. Because the applicant never consented and attempted to escape several times, the Court found that there was a violation of Art. 5(1). <i>Storck v. Germany</i>, no. 61603/00 (June 16, 2005).</p> <p><b>ECtHR:</b> The applicant, a mental health patient subject to internment, was detained in a prison where he subsequently committed suicide. The Court held there was a violation of Art. 5(1) because the detention was contrary to national law, which required the internment take place in a specialised institution, or at worst the psychiatric wing of a prison. The Court also recalled its finding in <i>Aerts v. Belgium</i>, 25357/94 (July 30, 1998) in which it held that the detention of a mentally ill person under Art. 5(1)(e) is only lawful if it is carried out in a hospital, clinic or other appropriate institution. <i>De-Donder and De Clippel v. Belgium</i>, 8595/06 (December 6, 2011).</p>

## Table 1: (Cont.)

### Other Interpretations

**UN Working Group on Arbitrary Detention:** “The Working Group has also been informed by several sources that, in some countries, the disabled, drug addicts and people suffering from AIDS are detained in places that are incompatible with their state of health, sometimes without treatment and without it having been established that their detention is justified on medical or public health grounds. The Group is concerned because it is vulnerable persons that are involved, people who are often stigmatized by social stereotypes; but it is concerned above all because often such administrative detention is not subject to judicial supervision.” E/CN.4/2004/3 (December 15, 2003), ¶ 74. (See also, E/CN.4/2005/6 (December 1, 2004), ¶¶ 47-58 on psychiatric detention).

## Table 2: Patient Care and the Right to Privacy

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Patient medical information is open to all hospital staff, including those not involved in patient care.</li> <li>• Patients are forced to disclose their medical diagnosis to their employer in order to obtain sick leave from work.</li> <li>• Medical examinations take place under public conditions.</li> <li>• Terminally ill patients are forced to remain in public wards.</li> <li>• Staff of medical/psychiatric institutions routinely open patient mail and review their correspondence.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<b>CESCR General Comment No. 14 (12):</b> While highlighting the importance of information accessibility in health care, CESCR says that State Parties “should not impair the right to have personal health data treated with confidentiality.”
<b>CRC 16(1):</b> No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.	<b>CRC General Comment No. 4:</b> Encouraging state parties to strictly protect adolescent health privacy and describing health care provider obligations to maintain privacy of adolescent patients; suggesting state parties enact legislation to protect adolescent patient privacy; and drawing attention to patient confidentiality and privacy component living in CESCR’s commitment to the highest attainable standard of health. CRC/GC/2003/4 (2003), ¶ 11, 33, 40.  <b>CRC:</b> Highlighting the need for confidentiality for adolescents with respect to sexual and reproductive health in <b>Djibouti</b> . CRC/C/97 (2000), para 555.
<b>CEDAW 12 (1).</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.  <b>CEDAW 12(2).</b> Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.	<b>CEDAW:</b> Recommending that <b>Paraguay</b> “adopt a policy for patient privacy, to safeguard doctor-patient confidentiality specifically when treating women for abortion complications.” CEDAW/C/PRY/CO/6 (2011), para. 31.

**Table 2: (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 8(1).</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><b>ECHR 8(2).</b> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p><b>ECtHR:</b> The applicant’s medical records were sent from her clinic to the Social Insurance Office without her knowledge or consent. The Court held that “the protection of personal data, particularly medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life . . . . Respecting the confidentiality of health data is a vital principle . . . . It is crucial not only to respect the sense of privacy of the patient but also to preserve his or her confidence in the medical profession and in the health services in general.” <i>M.S. v. Sweden</i>, 20837/92 (August 27, 1997).</p> <p><b>ECtHR:</b> The applicant’s medical records, including her HIV diagnosis, were included in her husband’s trial against her will, and the trial record was subsequently made public. The Court noted that disclosure of health data “may dramatically affect [a person’s] private and family life, as well as social and employment situation, by exposing him or her to opprobrium and the risk of ostracism.” <i>Z. v. Finland</i>, 22009/93 (February 25, 1997).</p> <p><b>ECtHR:</b> The applicant’s correspondence sent to him during at his stay at a psychiatric hospital was first sent to a curator who selected which correspondence to pass on to the applicant. Although Art. 8(2) permits violations of Art. 8(1) for the protection of health, the Court found that the hospital violated Art. 8, stating that there were no measures to ensure that the law permitting correspondence screening was not arbitrarily applied or to protect against arbitrary interference of Art. 8(1). <i>Herczegfalvy v. Austria</i>, 10533/83 (September 24, 1992).</p>

### Other Interpretations

#### Declaration of Lisbon on the Rights of the Patient, Principle 8: Right to Confidentiality.

- All identifiable information about a patient’s health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death. Exceptionally, descendants may have a right of access to information that would inform them of their health risks.
- Confidential information can only be disclosed if the patient gives explicit consent or if expressly provided for in the law. Information can be disclosed to other health care providers only on a strictly “need to know” basis unless the patient has given explicit consent.
- All identifiable patient data must be protected. The protection of the data must be appropriate to the manner of its storage. Human substances from which identifiable data can be derived must be likewise protected.

#### Declaration on the Promotion of Patients’ Rights in Europe:

Art. 4.1: All information about a patient’s health status . . . must be kept confidential, even after death.

Art. 4.8: Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy.

#### Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data.

##### European Convention on Human Rights and Biomedicine:

Art 10(1): Everyone has the right to respect for private life in relation to information about his or her health.”

Explanatory Report, Para.63: The first paragraph establishes the right to privacy of information in the health field, thereby reaffirming the principle introduced in Article 8 of the European Convention on Human Rights and reiterated in the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data. It should be pointed out that, under Article 6 of the latter Convention, personal data concerning health constitute a special category of data and are as such subject to special rules.

**European Charter of Patients’ Rights**, Art. 6: Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.

**Table 3: Patient Care and the Right to Information**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• A state fails to provide information on various health care services. For instance, rape victims are entitled to obtain post-exposure prophylaxis to prevent HIV infection, but very few are aware of this option.</li> <li>• Hospitals fail to provide information on patient satisfaction, clinical performance, and waiting lists.</li> <li>• Physicians fail to comprehensively explain to patients the facts related to their condition.</li> <li>• Physicians fail to provide patients with information about treatment options and the potential risks and benefits of each procedure.</li> <li>• Patients are denied access to their medical files.</li> <li>• Information services are unavailable for people who speak certain languages or who are deaf or blind.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR General Comment No. 14 (12):</b> Health care accessibility “includes the right to seek, receive and impart information and ideas concerning health issues.”</p>
<p><b>CEDAW 10</b> States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education and in particular to ensure, on a basis of equality of men and women:</p> <p><b>(h)</b> Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning.</p> <p><b>CEDAW 16(1)</b> States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women:</p> <p><b>(e)</b> The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.</p>	<p><b>CEDAW [Jurisprudence]:</b> The petitioner was sterilized during a Caesarean section to remove a dead fetus. She signed the consent form while on the surgical table, in shock and without understanding of what sterilization meant. She argued that Hungary violated CEDAW 10(h) and 16(1) (e) because she had not received “specific information about the sterilization, the effects of the operation on her ability to reproduce, or advice on family planning and contraceptive measures — either immediately before the operation or in the months/years before the operation was carried out. She claims that she was not given information about the nature of the operation, the risks and consequences, in a way that was comprehensible to her before she was asked to sign the consent form.” The Committee reasoned that “the author has a right protected by article 10(h) of the Convention to specific information on sterilization and alternative procedures for family planning in order to guard against such an intervention being carried out without her having made a fully informed choice. Furthermore, the Committee notes the description given of the author’s state of health on arrival at the hospital and observes that any counselling that she received must have been given under stressful and most inappropriate conditions. Considering all these factors, the Committee finds a failure of the State party, through the hospital personnel, to provide appropriate information and advice on family planning, which constitutes a violation of the author’s right under article 10 (h) of the Convention.” <i>A.S. v. Hungary</i>, Communication No. 4/2004, CEDAW/C/36/D/4/2004.</p>

**Table 3: (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 8(2).</b> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p><b>ECtHR:</b> The applicants, eight women of Roma origin, could not conceive any longer after being treated at gynaecological departments in two different hospitals. They suspected that it was because they had been sterilised during their stay in those hospitals. The hospitals refused to release their medical records to their authorised legal representative or to allow them to obtain a photocopy of the documents. The women then obtained judicial orders permitting them to consult the records under the Health Care Act 1994, but were not allowed to make photocopies. The Court found that this violated Art. 8. Since this case was filed, the Health Care Act 2004 now explicitly provides for patients or persons authorised by them to make copies of medical records. <i>K.H. and Others v. Slovakia</i>, 32881/04 (April 28, 2009)</p> <p><b>ECtHR:</b> The applicant, a serviceman, complained about inadequate access to information about the tests performed on him at a defence establishment. The defence establishment conducted research into chemical weapons for the UK's armed forces, including tests of gases on humans and animals. The Court found that "the State has not fulfilled the positive obligation to provide an effective and accessible procedure enabling the applicant to have access to all relevant and appropriate information that would allow him to assess any risk to which he had been exposed during his participation in the tests." <i>Roche v. United Kingdom</i>, 32555/96 (October 19, 2005).</p>

### Other Interpretations

#### **Declaration of Lisbon on the Rights of the Patient, Principle 7: Right to Information.**

- The patient has the right to receive information about himself/herself recorded in any of his/her medical records, and to be fully informed about his/her health status including the medical facts about his/her condition. However, confidential information in the patient's records about a third party should not be given to the patient without the consent of that third party.
- Exceptionally, information may be withheld from the patient when there is good reason to believe that this information would create a serious hazard to his/her life or health.
- Information should be given in a way appropriate to the patient's culture and in such a way that the patient can understand.
- The patient has the right not to be informed on his/her explicit request, unless required for the protection of another person's life.
- The patient has the right to choose who, if anyone, should be informed on his/her behalf.

#### **Declaration on the Promotion of Patients' Rights in Europe:**

Art. 2.2: Patients have the right to be fully informed about their health status, including the medical facts about their conditions; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis, and progress of treatment.

Art. 2.6: Patients have the right to choose who, if any one, should be informed on their behalf.

**European Convention on Human Rights and Biomedicine, Art. 10(2):** Everyone is entitled to know any information collected about his or her health. See *also* Explanatory Report, paras. 65-70 (interpreting the right to private life and right to information).

**European Charter of Patients' Rights, Art. 3:** Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available.



**Table 4: Patient Care and the Right to Bodily Integrity**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>Physicians either fail to obtain consent from patients before performing medical procedures, or do not provide patients with enough information to make an informed decision.</li> <li>In the case of a very young patient or a patient lacking capacity, the hospital does not allow for a substitute decision-maker.</li> <li>A hospital lacks standardized procedures for obtaining patients' consent to participate in scientific research.</li> <li>Physicians ignore patient wishes regarding treatment.</li> <li>Patients are not allowed to switch physicians or health care providers.</li> </ul>

**Note On Bodily Integrity in International and National Treaties:** The right to bodily integrity is not specifically recognized under the ICCPR, ICESCR, or European conventions, but has been interpreted to be part of the right to security of the person (ICCPR 9, ECHR 5); the right to freedom from torture and cruel, inhuman, and degrading treatment (ICCPR 7, ECHR 3); the right to privacy (ICCPR 17, ECHR 8); and the right to the highest attainable standard of health (ICESCR 12, ESC 11).

Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<b>CESCR General Comment No. 14(8):</b> Explaining that the right to health includes “the right to be free from torture, non-consensual medical treatment and experimentation.”

Human Rights Standards	Case Law
<b>ECHR 8(1).</b> Everyone has the right to respect for his private and family life, his home and his correspondence.	<p><b>ECtHR:</b> Pregnant mother wanted access to genetic test to determine the health of her child within the time-limit for abortion to remain a lawful option. The Court stated that “[c]ompliance with the State’s positive obligation to secure to their citizens their right to effective respect for their physical and psychological integrity may necessitate, in turn, the adoption of regulations concerning access to information about an individual’s health.” The Court also reasoned that the “right of access to such information falling within the ambit of the notion of private life can be said to comprise, in the Court’s view, on the one hand, a right to obtain available information on one’s condition. The Court further consider[ed] that during pregnancy the foetus’ condition and health constitute[s] an element of the pregnant woman’s health.” The Court therefore found a violation of Art. 8. <i>R. R. v. Poland</i>, 27617/04 (May 26, 2011).</p> <p><b>ECtHR:</b> “The imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person’s physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention.” <i>Pretty v. United Kingdom</i>, 2346/02 (Apr. 29, 2002), para. 83.</p> <p><b>ECtHR:</b> “The applicants maintained that the decisions to administer diamorphine to the first applicant against the second applicant’s wishes and to place a DNR notice in his notes without the second applicant’s knowledge interfered with the first applicant’s right to physical and moral integrity as well as with the second applicant’s Article 8 rights. . . . The Court considers that, having regard to the circumstances of the case, the decision of the authorities to override the second applicant’s objection to the proposed treatment in the absence of authorisation by a court resulted in a breach of Article 8. . . .” <i>Glass v. United Kingdom</i>, 61827/00 (Mar. 9, 2004).</p> <p><b>ECtHR:</b> “The applicant complained that her right to respect for her private and family life had been violated as a result of her sterilisation without her full and informed consent.” The Court found that there was a violation of Art. 8. <i>V.C. v. Slovakia</i>, 18968/07 (November 8, 2011).</p>



**Table 4: (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 8(1).</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p>	<p><b>ECtHR:</b> The applicant, NB, was sterilized while undergoing a Caesarean section at a public hospital. However, NB was only 17 years old at the time of the intervention, so she was also legally a minor. The hospital, in addition to having NB sign the consent form after the administration of tranquilizing pre-medication, never obtained the consent of her legal guardians. NB did not learn of her sterilization until several months after the fact because it was not noted in her release report from the hospital. The Court unanimously held that NB had been sterilized without informed consent and in contravention of Articles 8 and 13. <i>N.B. v. Slovakia</i>, 29518/10 (June 12, 2012).</p> <p><b>ECtHR:</b> Between 1977 and 1979, the applicant was placed in a clinic against her will, where she was immobilized and received medical treatment against her will. The Court found that “[i]n so far as the applicant argued that she had been medically treated against her will while detained, the Court reiterates that even a minor interference with the physical integrity of an individual must be regarded as an interference with the right to respect for private life under Article 8 if it is carried out against the individual’s will.” The Court also found that she was administered medication against her will and that this too constituted an interference with her right to respect for her private life under Art. 8. <i>Storck v. Germany</i>, 61603/00 (June 16, 2005).</p> <p><b>ECtHR:</b> Following police custody, the applicant alleged that the police forced a gynaecological examination of his wife by a doctor without her consent. The Court found that there was no consent and that “in the circumstances, the applicant’s wife could not have been expected to resist submitting to such an examination in view of her vulnerability at the hands of the authorities who exercised complete control over her throughout her detention.” The Court held that there was a violation of Art. 8. <i>Y.F. v. Turkey</i>, 24209/94 (July 22, 2003).</p>

### Other Interpretations

**World Medical Assembly, Declaration of Tokyo: Guidelines for Physicians Concerning Torture and other Cruel, Inhuman or Degrading Treatment or Punishment in Relation to Detention and Imprisonment** ([www.wma.net/en/2oactivities/1oethics/2otokyo/index.html](http://www.wma.net/en/2oactivities/1oethics/2otokyo/index.html))

#### European Charter of Patients’ Rights

Art. 4: A patient has the right to refuse a treatment or a medical intervention and to change his or her mind during the treatment, refusing its continuation.

Art. 5: The patient has the right to freely choose from among different treatment procedures and providers on the basis of adequate information.

#### Declaration on the Promotion of Patients’ Rights in Europe

Art. 3.1: The informed consent of the patient is a prerequisite for any medical intervention.

Art. 3.2: A patient has the right to refuse or halt a medical intervention.

**European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment** (2001) stated that “every competent patient...should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances.”

**European Convention on Human Rights and Biomedicine**, Art. 5: An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. See also Explanatory Report, paras. 34-40 (interpreting the general rule of consent found in the European Convention on Human Rights and Biomedicine).

**Table 5: Patient Care and the Right to Life**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Due to inadequate reproductive health and prenatal care, complications from pregnancy and childbirth are a leading cause of death for young women.</li> <li>• Ambulances fail to arrive at certain communities in a timely manner.</li> <li>• Patients are unable to obtain low-cost medications due to bureaucratic hurdles and an overly restrictive patent regime. As a result, their life is in danger.</li> <li>• Health services do not include preventive screening for many types of cancer. As a result, patients learn they have cancer when it is already too late for effective treatment.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1):</b> The States' Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<b>CESCR General Comment No. 14(1):</b> Explaining that “Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.”
<b>ICCPR 6(1):</b> Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.	<p><b>HRC General Comment No. 6 (1 and 5):</b> Explaining that the right to life “should not be interpreted narrowly” or “in a restrictive manner,” and its protection “requires that States adopt positive measures . . . to increase life expectancy.”</p> <p><b>HRC [Jurisprudence]:</b> The Committee considered whether the State party had failed in its obligations regarding Articles 6 and 2 of the Covenant in connection with the death of the author’s son as a result of inadequate medical treatment. The Committee found that there was insufficient evidence before it to attribute direct responsibility to the State for failure to meet its obligation under article 6 of the Covenant. Nevertheless, it found that there had been a breach of the State party’s obligation under the Covenant to properly investigate the death of the victim and take appropriate action against those responsible, which amounted to a violation of Article 2, paragraph 3, in conjunction with article 6 of the Covenant. <i>Novakovi v. Serbia</i>, Communication No. 1556/2007, CCPR/C/100/D/1556/2007.</p>

Human Rights Standards	Case Law
<b>ECHR 2(1):</b> Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.	<p><b>ECtHR:</b> holding that a violation of the right to life occurs “where it is shown that the authorities . . . put an individual’s life at risk through the denial of health care which they have undertaken to make available to the population generally.” <i>Cyprus v. Turkey</i>, 25781/94 (May 10, 2001), para. 219. See also, <i>Nitecki v. Poland</i>, 65653/01 (March 21, 2002) (stating same principle of law).</p> <p><b>ECtHR:</b> The applicants’ son, who sought medical assistance for nausea and itching skin, died in hospital after he was injected with drugs to which he was allergic. The applicants complained that their son died because of medical negligence and that there had been no effective investigation into his death. The Court found that “the domestic authorities failed to deal with the applicants’ claim arising out of their son’s death with the level of diligence required by Article 2,” finding that its procedural aspects had been violated. <i>Silih v. Slovenia</i>, 71463/01 (April 9, 2009).</p> <p><b>ECtHR:</b> “The Grand Chamber . . . finds that the embryos created by the applicant and J. do not have a right to life within the meaning of Article 2 of the Convention . . . .” <i>Evans v. United Kingdom</i>, 6339/05 (April 10, 2007).</p>

**Table 5: (cont.)****Other Interpretations**

**Colombia:** The Colombian Constitutional Court established that “the right to health was enforceable when it was inextricably related to enabling a life of dignity – and not merely preventing imminent death” and on this doctrine has ordered antiretroviral and cancer medications, financing treatment abroad for acute leukemia, treatment of severe depression, post-mastectomy breast implants, administration of growth hormones, and care for severe vision problems.

**Table 6: Patient Care and the Right to the Highest Attainable Standard of Physical and Mental Health**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Hospitals do not take adequate measures to prevent hospital-borne infections, oversee health risks following transfusions, and ensure that their tests and treatment remain of high quality.</li> <li>Hospitals fail to meet the needs of patients who require religious or psychological support, or do not provide treatment appropriate for the terminally ill.</li> <li>Hospitals fail to provide care suited to the needs of small children.</li> <li>Long, unjustified delays in the provision of health services regularly lead to a worsening in patients' health.</li> <li>A state lacks adequate compensation procedures for patients harmed by health care providers.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p> <p><b>ICESCR 12(2)</b> The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . .</p> <p><b>(c)</b> The prevention, treatment and control of epidemic, endemic, occupational and other diseases;</p> <p><b>(d)</b> The creation of conditions which would assure to all medical service and medical attention in the event of sickness.</p>	<p><b>CESCR General Comment No. 14</b> (3-4): explaining that Art. 12(1) speaks of “the highest attainable standard of physical and mental health” and that this standard might depend on economic capacity and capabilities and will hardly ever reach a state in which all persons are entirely healthy.</p> <p><b>CESCR General Comment No. 14</b> (4): explaining that “[t]he right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life.”</p> <p><b>CESCR General Comment No. 14</b> (12): explaining that, “[a]s well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality.” They must also be “sensitive to gender and life-cycle requirements....”</p> <p><b>CESCR:</b> pointing to a need for federal legislation on patient rights in <b>Russia</b>, including redress for medical errors. E/C.12/1/ADD.94 (CESCR, 2003).</p>
<p><b>CEDAW 12(1)</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p> <p><b>(2)</b> Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.</p>	<p><b>CEDAW Committee [Jurisprudence]:</b> finding Brazil in violation of Art.12 (2). The applicant's daughter was pregnant and died because of a delay in obtaining proper emergency care during a complicated pregnancy. The Committee noted that Brazil had adopted policies to address maternal health but referred to “general recommendation No. 28 (2010) on the core obligations of States parties under article 2 of the Convention and notes that the policies of the State party must be action- and results-oriented as well as adequately funded.” The Committee found that “the State party violated its obligations under article 12 (in relation to access to health), article 2 (c) (in relation to access to justice) and article 2 (e) (in relation to the State party's due diligence obligation to regulate the activities of private health service providers), in conjunction with article 1, of the Convention, read together with general recommendations Nos. 24 and 28.” The Committee recommended, among other things, that the State party must “[e]nsure women's right to safe motherhood and affordable access for all women to adequate emergency obstetric care, in line with general recommendation No. 24 (1999) on women and health.” <i>Alyne da Silva Pimentel v. Brazil</i>, CEDAW/C/49/D/17/2008.</p>

**Table 6: (cont.)**

Human Rights Standards	Case Law
<p><b>ACHPR 16(1)</b> Every individual shall have the right to enjoy the best attainable state of physical and mental health.</p> <p><b>ACHPR 16(2)</b> States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.</p>	<p><b>ACHPR (Committee):</b> “African jurisprudence places a premium on both the right to health care and the right to the underlying conditions of health. In the Purohit case, the African Commission held that the right to health in the African Charter on Human and Peoples’ Rights includes the right to health facilities, access to goods and services to be guaranteed to all without discrimination of any kind. (<i>Purohit and Moore v. The Gambia</i>, Communication 241/2001, para 80.) It has been confirmed that the underlying conditions for achieving a healthy life are protected by the right to health. Thus lack of electricity, drinking water and medicines amount to a violation of the right to health. The Zaire case, 2(<i>Free Legal Assistance Group and Others v Zaire</i>, Communications No 25/89, 47/90, 56/91, 100/93) concerning Article 16 of the African Charter on Human and Peoples’ Rights, confirmed that the failure of the government of Zaire to provide the mentioned basic services amounted to an infringement of the right to health.” IHRDA and Open Society Justice Initiative (OSJI) (on behalf of children of Nubian descent in Kenya) <i>v Kenya</i>, Communications No 002/09.</p> <p><b>ACHPR (Commission):</b> “The State’s responsibility in the event of detention is even more evident to the extent that detention centres are its exclusive preserve, hence the physical integrity and welfare of detainees is the responsibility of the competent public authorities. Some prisoners died as a result of the lack of medical attention. The general state of health of the prisoners deteriorated due to the lack of sufficient food; they had neither blankets nor adequate hygiene. The Mauritanian state is directly responsible for this state of affairs and the government has not denied these facts. Consequently, the Commission considers that there was a violation of [the right to health].” <i>Malawi African Association, Amnesty International, Ms Sarr Diop, Union interafricaine des droits de l’Homme and RADDHO, Collectif des veuves et ayants-Droit, Association mauritanienne des droits de l’Homme / Mauritania</i>, Communication No. 54/91-61/91-96/93-98/93-164/97-196/97-210/98.</p>

**Other Interpretations**

**Declaration of Lisbon on the Rights of the Patient**, Principle 1: Right to medical care of good quality.

- a. Every person is entitled without discrimination to appropriate medical care.
- b. Every patient has the right to be cared for by a physician whom he/she knows to be free to make clinical and ethical judgements without any outside interference.
- c. The patient shall always be treated in accordance with his/her best interests. The treatment applied shall be in accordance with generally approved medical principles.
- d. Quality assurance should always be a part of health care. Physicians, in particular, should accept responsibility for being guardians of the quality of medical services.
- e. In circumstances where a choice must be made between potential patients for a particular treatment that is in limited supply, all such patients are entitled to a fair selection procedure for that treatment. That choice must be based on medical criteria and made without discrimination.
- f. The patient has the right to continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care.

**Declaration on the Promotion of Patients’ Rights in Europe**, Art. 5.3: “Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider.”

**European Charter of Patients’ Rights.**

**International Alliance of Patients’ Organizations: Declaration on Patient-Centered Health Care** (March 30, 2007), ([www.patientsorganizations.org/](http://www.patientsorganizations.org/)).

**Table 7: Patient Care and Freedom from Torture and Cruel, Inhuman, and Degrading Treatment**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Victims of state torture are denied needed medical care.</li> <li>• Prisoners lack basic health services and are forced to subsist on very little food and with inadequate clothes and no heat during the winter.</li> <li>• Mentally ill prisoners are punished for symptoms of their illness, including self-mutilation and attempted suicide.</li> <li>• National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 7:</b> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.</p>	<p><b>HRC [Jurisprudence]:</b> The author claimed that by preventing her daughter, who has a permanent mental impairment, from obtaining a termination of pregnancy, as permitted under the State's criminal law, the State party violated her rights under the ICCPR. The State's criminal law permits female rape victims with a mental disability the right to terminate a pregnancy. The Committee found a violation of Art. 7, Art. 17 and Art. 2(3) in relation to Arts. 3, 7 and 17. <i>L.M.R. v. Argentina</i>, CCPR/C/101/D/1608/2007 (2011).</p> <p><b>HRC:</b> calling for the improvement of hygienic conditions, regular exercise, and adequate treatment of the mentally ill in detention facilities in <b>Bosnia and Herzegovina</b> (both in prisons and mental health institutions). CCPR/C/BIH/CO/1 (HRC, 2006), para. 19.</p>

Human Rights Standards	Case Law
<p><b>ECHR 3</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.</p>	<p><b>ECtHR:</b> holding that states have a duty to protect the health of detainees and lack of treatment may amount to a violation of the right to freedom from torture or to inhuman or degrading treatment. <i>Hurtado v. Switzerland</i>, 17549/90 (January 28, 1994).</p> <p><b>ECtHR:</b> The applicant did not receive timely prenatal genetic testing that would have allowed her to make a decision to legally abort her pregnancy. The Court found that the determination of whether she should have access to genetic testing “was marred by procrastination, confusion and lack of proper counselling and information given to the applicant” and that the lack of regard of the patient’s rights and her suffering amounted to a violation of Art. 3. <i>R.R. v. Poland</i>, 27617/04 (May 26, 2011).</p> <p><b>ECtHR:</b> holding that the failure to respond adequately to the prisoner’s deteriorating mental health amounted to inhuman or degrading treatment or punishment. <i>Keenan v. United Kingdom</i>, 27229/95 (April 3, 2001).</p> <p><b>ECtHR:</b> holding “that there has been a violation of Article 3 of the Convention as regards the lack of adequate medical treatment and assistance provided to the applicant while he was detained, amounting to degrading treatment.” <i>Nevmerzhitsky v. Ukraine</i>, 54825/00 (April 5, 2005).</p> <p><b>ECtHR:</b> in discussing what constitutes a violation of Article 3 for prisoners, “[t]he Court observes that there are three particular elements to be considered in relation to the compatibility of an applicant’s health with his stay in detention: (a) the medical condition of the prisoner, (b) the adequacy of the medical assistance and care provided in detention, and (c) the advisability of maintaining the detention measure in view of the state of health of an applicant . . .” The applicant in this case suffered “chronic and severe mental disorders including schizophrenia” and was held in an ordinary detention center without special medical attention. The Court held “that the nature, duration and severity of the ill-treatment to which the applicant was subjected are sufficient to be qualified as inhuman and degrading.” <i>Musial v. Poland</i>, 28300/06 (January 20, 2009).</p>

**Table 7: (cont.)**

Human Rights Standards	Case Law
<b>ECHR 3</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.	<b>ECtHR:</b> examining whether there was a violation of Art. 3 after the applicant was held in a police station cell despite his psychological disorders, which were registered by public authorities as a second-degree disability. The Court found that the authorities were “under an obligation to have him examined by a psychiatrist as soon as possible in order to determine whether his psychological condition was compatible with detention, and what therapeutic measures should be taken” and that this lack of medical attention violated Art. 3. <i>Rupa v. Romania</i> , 58478/00 (December 16, 2008).

**Other Interpretations**

**Committee Against Torture:** Noting overcrowding, inadequate living conditions, and lengthy confinement in **Russian** psychiatric hospitals, which may be “tantamount to inhuman or degrading treatment.” CAT/C/RUS/CO/4 (CAT, 2006), para. 18.

**World Medical Assembly, Declaration of Tokyo: Guidelines for Physicians Concerning Torture and other Cruel, Inhuman or Degrading Treatment or Punishment in Relation to Detention and Imprisonment** ([www.wma.net/en/20activities/10ethics/20tokyo/index.html](http://www.wma.net/en/20activities/10ethics/20tokyo/index.html)).

**Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment**, G.A. Res. 37/194, UN Doc. No. A/RES/37/194 (Dec. 18, 1982) (<http://www2.ohchr.org/english/law/medicaethics.htm>).

**Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment** (1999) ([www.ohchr.org/Documents/Publications/training8Rev1en.pdf](http://www.ohchr.org/Documents/Publications/training8Rev1en.pdf)).

**Code of Conduct for Law Enforcement Officials**, G.A. Res. 34/169, UN Doc. A/RES/34/169 (Dec. 17, 1979) (<http://www2.ohchr.org/english/>).

**The European Charter of Patients' Rights**, Art. 11: Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative treatments and simplifying patients' access to them.

**Declaration on the Promotion of Patients' Rights in Europe**, Art. 5.10: Patients have the right to relief of their suffering according to the current state of knowledge. Art. 5.11: Patients have the right to humane terminal care and to die in dignity.

**Table 8: Patient Care and the Right to Participate in Public Policy**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• A country fails to adopt a national health plan or to make it publicly available to its citizens.</li> <li>• Citizens lack an opportunity to comment on and participate in the setting of public health priorities.</li> <li>• The government will not accept or respond to information and proposals on health care delivery submitted by citizens.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<p><b>CESCR General Comment No. 14</b> (43): calling for countries to adopt “a national public health strategy and plan of action” to be “periodically reviewed, on the basis of a participatory and transparent process . . . .”</p> <p><b>CESCR General Comment No. 14</b> (54): explaining that “[p]romoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people’s participation is secured by States.”</p>



## Table 8: (cont.)

### Other Interpretations

**Ljubljana Charter on Reforming Health Care**, World Health Organization (1996), Fundamental Principle 5.3: “Health care reforms must address citizens’ needs taking into account, through the democratic process, their expectations about health and health care. They should ensure that the citizen’s voice and choice decisively influence the way in which health services are designed and operate. Citizens must also share responsibility for their own health.”

**The European Charter of Patients’ Rights**, Rights of Active Citizenship (Part III): Citizens have the “right to participate in the definition, implementation and evaluation of public policies relating to the protection of health care rights.”

Alicia Ely Yamin, “The Right to Health Under International Law and Its Relevance to the United States.” *American Journal of Public Health* 95(7) (July 2005), doi: 10.2105/AJPH.2004.055111.: “Realization of the right to health further implies providing individuals and communities with an authentic voice in decisions defining, determining, and affecting their well-being. Public health has a long tradition of recognizing that participation is integral to health promotion.”

## Table 9: Patient Care and the Right to Non-Discrimination and Equality

### Examples of Human Rights Violations

- Members of certain communities are treated in separate ways with a lower standard of care.
- Health workers refuse to treat sex workers, drug workers or LGBT persons.
- Maternal and reproductive health services for women are lacking.
- A country fails to provide health services to the poor or non-citizens.

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 2(2)</b> The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenants will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</p> <p><b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR General Comment 20:</b> In explaining “other status” under ICESCR 2(2), CESCR explains “Health status refers to a person’s physical or mental health. States parties should ensure that a person’s actual or perceived health status is not a barrier to realizing the rights under the Covenant. The protection of public health is often cited by States as a basis for restricting human rights in the context of a person’s health status. However, many such restrictions are discriminatory, for example, when HIV status is used as the basis for differential treatment with regard to access to education, employment, health care, travel, social security, housing and asylum. States parties should also adopt measures to address widespread stigmatisation of persons on the basis of their health status, such as mental illness, diseases such as leprosy and women who have suffered obstetric fistula, which often undermines the ability of individuals to enjoy fully their Covenant rights. Denial of access to health insurance on the basis of health status will amount to discrimination if no reasonable or objective criteria can justify such differentiation.” E/C.12/GC/20 (June 10, 2009).</p> <p><b>CESCR General Comment 14:</b> “With respect to the right to health, equality of access to health care and health services has to be emphasized. States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds in the provision of health care and health services, especially with respect to the core obligations of the right to health.”</p> <p><b>CESCR General Comment No. 14 (14):</b> Explaining that “health facilities, goods and services must be accessible to all [without discrimination], especially to the most vulnerable and marginalized sections of the population . . .” The Committee stated that this included the health care access needs of “ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS.”</p>

**Table 9: (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 12(1)</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p>	<p><b>CEDAW Committee General Recommendation No. 19 (19-20):</b> explaining that “States parties are required by Article 12 to take measures to ensure equal access to health care. Violence against women puts their health and lives at risk. In some States there are traditional practices perpetuated by culture and tradition that are harmful to the health of women and children. These practices include dietary restrictions for pregnant women, preference for male children and female circumcision or genital mutilation.”</p>

### Other Interpretations

**Declaration of Lisbon on the Rights of the Patient:** Principle 1: Right to medical care of good quality:

- a. Every person is entitled without discrimination to appropriate medical care.
- e. In circumstances where a choice must be made between potential patients for a particular treatment that is in limited supply, all such patients are entitled to a fair selection procedure for that treatment. That choice must be based on medical criteria and made without discrimination.

**Declaration of Alma-Ata:** (V) Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. ... (VIII) All governments should formulate national policies, strategies and plans of action to launch and sustain primary health care as part of a comprehensive national health system and in coordination with other sectors. To this end, it will be necessary to exercise political will, to mobilize the country's resources and to use available external resources rationally.

**European Convention on Human Rights and Biomedicine,** Art. 3: Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality. See also Explanatory Report, paras. 24-27 (interpreting the right to equitable access to health care provided by article 3 of the European Convention on Human Rights and Biomedicine).

**Covenant on the Rights of the Child in Islam,** as adopted by the Organization of the Islamic Conference (OIC), art. 15. The child [regardless of minority status] is entitled to physical and psychological care.



### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>43</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>44</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>45</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>46</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>43</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>44</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>45</sup> Ibid.

<sup>46</sup> Ibid.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>47</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>47</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

- A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:
- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

## 4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF PATIENT CARE?

This section contains **five examples** of effective human rights-based work in the area of patient care and human rights. These are:

1. Litigating to protect private patient medical records in Ukraine
2. Monitoring and advocacy on patient rights at the European level
3. Training and litigation guides: The Practitioner Guide project
4. Human rights in patient care course initiative
5. Uganda National Health Consumers' Organisation: Developing a patients' charter

## Example I: Litigating to protect private patient medical records in Ukraine

### Ukraine Court Decision: Medical Certificate and Privacy

<http://cop.health-rights.org/teaching/54/Ukraine-Court-Decision--Medical-Certificate-and-Privacy>

#### Project Type

Litigation

#### The Organization

Vinnitsa Human Rights Group (Vinnitsa) is a civil society organization concerned with promoting the rule of law, as well as heightening individual political and legal awareness. The organization works to facilitate the harmonization of Ukrainian law with European human rights standards, with a particular focus on the rights of patients and refugees. In this case, Vinnitsa facilitated a civil action brought by a Ukrainian citizen whose right to patient privacy had been violated.

#### The Problem

To receive disability benefits in Ukraine at the time this case was first heard, an applicant's medical certificate documenting his/her diagnosis had to be forwarded to his/her employer. Mrs. Svitlana Yuriyivna Poberezhets, a Ukrainian citizen seeking disability benefits, challenged the release of her private medical information to her employer on the basis of the Ukrainian Constitution, the European Convention for the Protection of Human Rights and Fundamental Freedoms, and various Ukrainian civil codes.

#### Procedure

Vinnitsa Human Rights Group brought an administrative claim in the Pecherskyi District Court in Kyiv on behalf of Poberezhets. The claim was brought against the Ministry of Health of Ukraine, the Ministry of Labor and Social Policy of Ukraine, the Social Insurance Fund for Temporary Disability, and the Social Insurance Fund for Industrial Accidents and Occupational Disease of Ukraine.

### Rights Violations

**Ukrainian Const. Art. 32:** The collection, storage, use, and dissemination of confidential information about a person without his or her consent shall not be permitted, except in cases determined by law, and only in the interest of national security, economic welfare, and human rights. Ukrainian Constitution:

[www.ccu.gov.ua/en/doccatalog/list?currDir=12083](http://www.ccu.gov.ua/en/doccatalog/list?currDir=12083).

**EHCR Art. 8:** Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

EHCR: <http://tinyurl.com/3ydyjvo>.

**Ukrainian Civil Code:** Ukraine adopted a new civil code, which entered into force on January 1, 2004. The code provided numerous protections for private data, which this court interpreted to include patient diagnosis. Ukrainian Civil Code: <http://zakon2.rada.gov.ua/laws/main/en/annot>.

### Arguments and Holding

Poberezhets sought a declaration that inclusion of her specific disease on her medical certificate constituted dissemination of confidential information, in violation of her rights under Article 32 of the Ukrainian Constitution. Article 32 states, “The collection, storage, use and dissemination of confidential information about a person without his or her consent shall not be permitted, except in cases determined by law, and only in the interest of national security, economic welfare and human rights.” As the court noted, the medical certificate was available for use in civil matters as a ground to release an employee from their responsibilities to their employer. It was also available for use in public relationships as a basis for disability benefits. Therefore, release of a medical certificate in this case constituted dissemination of information.

Moreover, there were no security, economic welfare, or human rights grounds to justify the release of information. Therefore, since Article 8 of the ECHR and various provisions of the Ukrainian Civil Code clearly established that a person’s diagnosis is private, confidential information, the requirement that the applicant’s specific medical status be disclosed to her employer was in violation of her rights under Article 32 of the Ukrainian Constitution. The administrative bodies could not force patients to turn over information related to their diagnosis as a condition for receiving disability benefits.

### Historical Note

Ukraine’s Soviet past has had a strong influence on its law and judicial procedure. The Constitution of the USSR protected privacy in principle (Article 56: “The privacy of citizens, and of their correspondence, telephone conversations, and telegraphic communications is protected by law”). However, provisions of the Soviet Constitution were not directly enforceable law, and the Soviet Union had little interest in enacting statutes protecting an individual’s right to privacy—indeed, “individual” was a taboo term. Moreover, Soviet-era courts only enforced rights where a specific statute existed establishing those rights. The courts did not venture out to balance laws or fill in the gaps within the statutory framework.

Now, Ukraine has ambitions to join the European Union, and patient confidentiality is a more pressing concern. Harmonization with the European human rights framework is an important goal of the Ukraine Government. Therefore, Ukraine is a more hospitable venue for human rights litigation, like the action taken by Vinnitsa, than it once was.

### Analysis and Commentary

Privacy and individual autonomy are the building blocks of democratic society. Over the past century, there has been an unusual strain on the right to privacy. On the one hand, technological advances lead to increasingly powerful and sophisticated means of collecting and distributing private data. At the same time, however, people gain greater respect for individuality and privacy, and they demand that legal systems protect their private medical data. Indeed, privacy is a broad term that evolves with the evolution of society, including the development of ever larger and more easily transmitted medical data depositories.

The protection of private medical information is of pressing concern in Ukraine today. Although Ukraine’s information technology infrastructure still lags behind EU member states, it is modernizing at an astonishing rate. In 2006, 4.4% of Ukraine’s population used the Internet. In 2011, that number was 30% (World Bank). Establishing a right to privacy with respect to medical data is especially important given the rapid pace of technological development in Ukraine and the corresponding potential for abuse of patient privacy.

**Vinnitsa Human Rights Group, Ukraine**

E-mail: [vpg@ukr.net](mailto:vpg@ukr.net), Web: <http://www.vpg.org.ua/>

## Example 2: Monitoring and advocacy on patient rights at the European level

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### Project Type

Advocacy

### The Organization

Created in December 2001, Active Citizens Network (ACN) is a network of European civil society organizations working to encourage active public participation in European policymaking. ACN's policies center on the issues of health and corporate social responsibility. They conduct education and training at the regional level.

### The Problem

While European Union countries valued the right to universal access to health care, ACN noted that budgetary restraints brought into question the quality of the health care system. Most notably, patients' rights were compromised and violated in health care provision, which is in contradiction to the social model of health care promoted by the European Union countries. ACN noted that “[b]udgetary constraints, however justified, cannot legitimize denying or compromising patients' rights.”

It is important to note that other trends also helped shape development of ACN. These developments included: increasing expense and rationing of health care services; the emergence of a consumer movement in Europe, and the demand for patients to play a more active role in managing their care and shaping their treatment; and increasing freedom of movement in the EU, which lead to interest in harmonization of basic standards.

### Actions Taken

***Drafting the European Charter of Patients' Rights.*** In 2002, the ACN and 15 citizens' organizations worked together to draft the European Charter of Patients' Rights. The principles of the charter aim to guarantee a “high level of human health protection” (Article 35 of the Charter of fundamental rights of the European Union). The purpose of drafting the charter was to raise awareness of patients' rights, which were at risk throughout Europe due to financial constraints on the health care system.

***Surveying implementation of the European Charter of Patients' Rights.*** In 2005, ACN conducted its first survey study of hospitals throughout the European Union (excluding Luxembourg) to measure the implementation of the European Charter of Patients' Rights. In 2007, ACN presented the final report in Brussels on the occasion of the First European Day of Patients' Rights. A follow-up monitoring was conducted from May to October 2010. [That monitoring report is available here.](#)

***Establishing a European Day of Patients' Rights.*** ACT established a day to discuss patients' rights across Europe. The European Parliament, EU Commission, and ESCC participated and provided support for this first European Day. In 2011, the EU Commission decided to officially support the Fifth European Day of Patients' Rights.

## European Charter of Patients' Rights

1. Right to preventive measures
2. Right of access
3. Right to information
4. Right to consent
5. Right to free choice
6. Right to privacy and confidentiality
7. Right to respect of patients' time
8. Right to the observance of quality standards
9. Right to safety
10. Right to innovation
11. Right to avoid unnecessary suffering and pain
12. Right to personalized treatment
13. Right to complain
14. Right to compensation

### Results and Lessons Learned

Since publishing the European Charter of Patients' Rights, there has been a dramatic improvement in the discussion of patients' rights across Europe, including significant publications by public institutions, citizens' organizations, and independent experts. Patients' rights are now a part of the European policy agenda. Public institutions are increasingly aware of their obligations to patients' rights. Finally, there is a greater recognition of the need to create common standards of medical practice to protect patients' rights across Europe.

**Active Citizenship Network (ACN)**, Rome, Italy

E-mail: [info@activecitizenship.net](mailto:info@activecitizenship.net), Web: [www.activecitizenship.net](http://www.activecitizenship.net)



## Example 3: Training and litigation guides: The Practitioner Guide Project

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### Project Type

Training and Litigation

### The Organization

The Practitioner Guide Project is an Open Society Foundations (OSF) project spearheaded by the Law and Health Initiative (LAHI) of the Public Health Program in collaboration with the Human Right and Governance Grants Program; Health Media Initiative; Roma Health Project; Russia Project; and National Foundations in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Moldova, and Ukraine.

OSF works to build vibrant and tolerant democracies whose governments are accountable to their citizens. Working with local communities in more than 70 countries, OSF supports justice and human rights, freedom of expression, and access to public health and education.

The Public Health Program aims to build societies committed to inclusion, human rights, and justice, in which health-related policies and practices reflect these values and are based on evidence. The program works to strengthen the capacity of organizations and leaders who represent marginalized communities to advocate for better health policies and practices. It also pushes for greater government accountability and transparency in health care.

LAHI supports the use of legal strategies to advance the health and human rights of marginalized and vulnerable groups. It advances this mission by applying the health and human rights framework to new issues and priority regions; developing individual and organizational leadership in the field of health and human rights; piloting innovative access to justice tools as health-related human rights interventions; advocating for rights-based legal environments that support the health of marginalized groups; and leveraging sustainable funding for efforts that advance this mission. The crux of this initiative is focused on the implementation of laws that protect the rights of both patients and providers.

### The Problem

Human rights norms are an increasingly important component of the delivery of quality medical care. OSF's work on behalf of society's most marginalized persons—people with disabilities, people living with HIV, people who use drugs, sex workers, Roma and other ethnic minorities—has shown that health systems can too often be places of punishment, coercion, and violations of basic rights to privacy and confidentiality, rather than places of treatment and care. At the same, health providers suffer from a lack of independence, decent working conditions, and due process protections. Laws in Eastern Europe and Central Asia have the potential to ensure accountability and address these violations, but they are rarely implemented. Additionally, in many of these countries, laws are rapidly in flux, and there is a dearth of materials providing updated guidance to navigate the various laws, as well as procedures for protection of rights through both the formal court system and alternate mechanisms, such as ombudspersons and ethics review committees.

### **Actions Taken**

LAHI, in collaboration with OSF partners, has supported the development of a series of Practitioner Guides and companion websites for lawyers interested in taking human rights in patient care cases—albeit patient rights or provider rights cases. The Practitioner Guides are practical how-to manuals covering both litigation and alternative dispute mechanisms. They examine patient and provider rights and responsibilities and procedural mechanisms at the national, regional, and international levels. Guides have been or are being produced in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Moldova, Serbia, Romania, Russia, and Ukraine. They can be accessed at <http://cop.health-rights.org/PractitionerGuides>.

### **Results and Lessons Learned**

Once published, Practitioner Guides are used as a basis for training and litigation support. They show particular potential as a resource in clinical legal education programs. Although legal practitioners are the primary audience for these guides, they are also useful for medical professionals, public health managers, Ministry of Health and Justice personnel, patient advocacy groups, and patients themselves.

Follow-up activities for this project include trainings for lawyers and judges, patient-friendly versions of the guides with a focus on marginalized populations, and potential law reform to address gaps identified by the Practitioner Guide working groups.

Since human rights in patient care are constantly evolving, electronic versions of the guides are periodically updated. The international home page, [www.health-rights.org](http://www.health-rights.org), links to country websites, which provide additional resources gathered by the country working groups that prepared each guide. These resources include relevant laws and regulations, case law, tools and sample forms, and practical tips for lawyers. The websites also provide a way to connect lawyers, health providers, and patients concerned about human rights in health care. Each website provides a mechanism for providing feedback on the guides.

**Open Society Foundation, Public Health Program, New York, USA**

Web: <http://www.opensocietyfoundations.org/about/programs/public-health-program>

**Health Rights: Human Rights in Patient Care**

<http://www.health-rights.org>

**Health Rights: Practitioner Guides**

<http://cop.health-rights.org/PractitionerGuides>

## Example 4: Human rights in patient care courses initiative

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### Project Type

Advocacy

### The Organization

The Law and Health Initiative (LAHI), a division of the Open Society Foundation's Public Health Program, supports the use of legal strategies to advance the health and human rights of marginalized and vulnerable groups. It advances this mission by applying the health and human rights framework to new issues and priority regions; developing individual and organizational leadership in the field of health and human rights; piloting innovative access to justice tools as health-related human rights interventions; advocating for rights-based legal environments that support the health of marginalized groups; and leveraging sustainable funding for efforts that advance this mission.

LAHI supports collaborations between health and legal practitioners with a view to advancing mutually shared goals of human rights, human dignity and open society. LAHI both builds the capacity of health providers to use the law to advance their advocacy objectives and supports legal practitioners in expanding their remit to include public health. This initiative was undertaken by LAHI in collaboration with the Human Rights and Governance Grants Program, Roma Health Project, Russia Project, and National Foundations in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Moldova, Serbia, and Ukraine of the Open Society Foundations.

### The Problem

Human rights norms are an increasingly important component of the delivery of quality medical care. OSF's work on behalf of society's most marginalized persons—people with disabilities, people living with HIV, people who use drugs, sex workers, Roma and other ethnic minorities—has shown that health systems can too often be places of punishment, coercion, and violations of basic rights to privacy and confidentiality, rather than places of treatment and care. At the same time, doctors and health practitioners in many Eastern European and Central Asian (EECA) countries are constrained in their ability to provide quality care to their patients, or are unaware of how to incorporate ethical and human rights norms into their work. Similarly, legal professionals have limited experience in working in health and trying to address the abuses that occur. There is a need to address this gap so that the next generation of doctors and health practitioners receive basic human rights training and legal professionals are equipped to work at the intersection of law and health.

### Actions Taken

LAHI, in collaboration with OSF partners, has sought to respond to this need by supporting the development of courses on human rights in patient care in nine EECA countries. In 2007, LAHI hosted a Salzburg seminar bringing together academics from EECA medical, public health, and law schools along with key partner NGOs and patient advocates for an intensive week to explore critical human rights in patient care topics and think creatively about how to structure a course addressing these issues. LAHI and OSF partners subsequently funded the development and piloting of over a dozen courses in Armenia, Georgia, Kazakhstan, Kyrgyzstan, Macedonia, Russia, Serbia, and Ukraine. Different courses target medical students, medical practitioners, health managers, public health students, and law students.

### **Results and Lessons Learned**

While the courses are self-sustaining and a regular part of the offerings at each university, faculty have requested the opportunity to share experiences and materials and continue to strengthen their teaching. To meet this need, LAHI and partners organized a series of workshops over the past few years. Workshops provided faculty with an opportunity to share lessons with each other, sharpen their interactive teaching methodology, and develop lesson plans and case studies. Faculty were also exposed to cutting edge health and human rights topics, such as access to sex reassignment surgery, access to maternal care for women who use drugs, coercive sterilization of women living with HIV, health care privatization and human rights, and dual loyalty conflicts faced by health practitioners. Additionally, LAHI and OSF's Health Media Initiative supported the development of an online "Community of Practice" for ongoing collaboration among faculty. Please find the Community of Practice web page at: <http://cop.health-rights.org/>.

**Open Society Foundations, Public Health Program, New York, USA**

Web: <http://www.opensocietyfoundations.org/about/programs/public-health-program>

## Example 5: Uganda National Health Consumers' Organization: Developing a patients' charter

### Project Type

Advocacy

### The Organization

Uganda National Health Consumers' Organization (UNHCO) is a health rights advocacy organization that empowers citizens to demand and hold service providers and policy makers accountable. It uses the rights-based approach to raise community awareness on the right to health, so that citizens view health as an entitlement and not a privilege. This approach also aims to make communities aware of the standards and guidelines at each level of service delivery, so they know what to demand, and what their responsibilities are for effective delivery of health services. Using this approach, communities are empowered to demand and participate in improving quality service delivery at each level of the health care system.

UNHCO establishes and strengthens mechanisms for engagement between consumers, service providers, and policy makers. The mechanisms include community dialogue meetings, suggestion boxes, and Health Unit Management Committees (HUMCs). Community members use the mechanisms to provide feedback about health service delivery. UNHCO also builds capacity of the community structures both existing and new including health workers, local politicians, partner Community Based Organizations (CBOs), and community advocates. The community structures are empowered to monitor and hold duty bearers accountable. They also increase health consumers' awareness about their rights and responsibilities, standards, and feedback and redress mechanisms.

In an effort to empower communities to engage service providers and policy makers, UNHCO employs social accountability tools in different communities of operation. The tools include citizens' report card and community score cards to generate issues for advocacy but also to cause duty bearers to address identified gaps in health care delivery.

### Right to High-Quality Health Care

Uganda Const. (Social and Economic Objective No. XX of the 1995): "The State shall take all practical measures to ensure the provision of basic medical services to the population."

Source: *Eastern Africa Centre for Constitutional Development*, [www.kituoachakatiba.org](http://www.kituoachakatiba.org)

### Patients' Charter

"The objective of the [P]atients' [C]harter is to empower health consumers to demand high quality health care, to promote the rights of patients and to improve the quality of life of all Ugandans and finally eradicate poverty nationwide."

*The Republic of Uganda, Patients' Charter (2009)*, <http://unhco.or.ug/library/?did=11>

To create a critical mass for advocacy for addressing community concerns both at the community and national level, UNHCO has led the formation of coalitions and alliances as need arises. UNHCO is currently leading the following coalitions: Voices for Health Rights (VHR), Coalition to Stop Maternal Mortality in Uganda, Communities of Change, CSO Coalition on Pharmaceutical Procurement and Supply Chain Management (PSM) for Accountability in Uganda, and the Health Accountability Platform.

### **The Problem**

According to the World Health Organization, Uganda ranks among the world's lowest in health status. Almost 30 years since the National Resistance Movement came to power in 1986, destruction of health infrastructure and loss of human resources continue to depress health care statistics. Indeed, Uganda attempts to provide health care services to a larger and rapidly growing population with fewer resources than it had in the 1970s. Moreover, the spreading of disease (particularly malaria, HIV/AIDS, tuberculosis, diarrhea, cholera, measles, and non-communicable diseases) and a general unawareness of legal rights make the delivery of health care in Uganda a particular challenge.

### **Actions Taken**

In an effort to legalize the right to health in Uganda, UNHCO spearheaded the development of the Patients' Charter, whose objective is to provide a policy and legal framework for empowerment of health consumers, enabling them to demand for high quality health care and promote accountability in the health sector. UNHCO continues to use the Patients' Charter as a tool for legalizing the right to health in Uganda.

UNHCO sits on different Ministry of Health committees to inform policy and practice. These include the Health Policy Advisory Committee (HPAC), Public Private Partnership in Health (PPPH), Sector Working Groups, and Quality Assurance Committees. Under these committees, UNHCO works to ensure that consumer concerns are part of the planning of the sector. It also ensures that the sector uses the rights-based approach in policy implementation.

UNHCO was instrumental in developing the Patients' Charter. The Charter adopts a rights-based approach to health care delivery and provides a policy and legal framework for health care consumers—enabling them to demand high quality care and accountability. The Ugandan Government adopted the Charter, and the Ugandan Ministry of Health (MOH) working in conjunction with UNHCO, is now taking steps towards implementing it.

## Patients' Charter—Patients' Rights:

1. The Right to Medical Care
2. Prohibition of Discrimination
3. Participation on Decision-making
4. A Healthy and Safe Environment
5. Proper Medical Care
6. Treated by a Named Health Care Provider
7. Participation in Training and Research (Voluntary, Informed and with Written or Verbal Consent)
8. Right to Safety and Security
9. Right to Receive Visitors
10. Right to Informed Consent
11. Limitations on Medical Care Without Consent
12. Right to Refuse Treatment
13. Right to Referral for Second Opinion
14. Continuity of Care
15. Right to Confidentiality and Privacy
16. Right to Medical Information
17. Custody of Medical Records
18. Medical Records Retention (Medical Archives)
19. Right to Redress

Source: <http://unhco.or.ug/wp-content/uploads/downloads/2011/02/Patients-Charter.pdf>

### Results and Lessons Learned

The Ugandan Government's commitment to working with civil society organizations to formulate a new health policy that provides greater access, transparency, and accountability is a great step toward better health care. The Charter specifically lays out the obligations of health care providers and the rights of health care consumers; however, considerable efforts are necessary to narrow the gap between health care policy and implementation.

For this reason, UNHCO began innovative work to ensure the implementation of the Patients' Charter, including an effort to spell out the rights and obligations contained therein to the health Sector Strategic Investment Plan III (HSSIP) (2010/11-2014/15). UNHCO also monitors HSSIP and the national budget to measure the extent to which they comport with the priorities of the HSSIP.

**Uganda National Health Consumers' Organization (UNHCO)**, Kampala, Uganda  
E-mail: [info@unhco.or.ug](mailto:info@unhco.or.ug), Web: <http://unhco.or.ug/>

## 5. WHERE CAN I FIND ADDITIONAL RESOURCES ON PATIENT CARE AND HUMAN RIGHTS?

A list of commonly used resources on patient care and human rights follows organized according to key topics highlighted within the text. It is organized into the following categories:

It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. General Resources
- D. Health Workers and Human Rights
- E. Right to Life
- F. Right to Information
- G. Right to Participate in Public Policy
- H. Right to Non-Discrimination and Equality
- I. Cross-Border Health In Europe
- J. Journals
- K. Websites

### A. International Instruments

- International Alliance of Patients' Organizations, *Declaration on Patient-Centered Health Care* (March 30, 2007). [www.patientsorganizations.org/showarticle.pl?id=712;n=312](http://www.patientsorganizations.org/showarticle.pl?id=712;n=312). Available in Spanish.
- UN Office of the High Commissioner for Human Rights, Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (2004). <http://www.ohchr.org/Documents/Publications/training8Rev1en.pdf>.
- UN Office of the High Commissioner for Human Rights. *Standard Minimum Rules for the Treatment of Prisoners* (adopted 1955). <http://www2.ohchr.org/english/law/treatmentprisoners.htm>.
- UNESCO General Conference, *Universal Declaration on Bioethics and Human Rights*, (October 19, 2005). [www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/](http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/).
- UN General Assembly, *Body of Principles for the Protection of All Persons Under Any Form of Detention*, Resolution 43/173 (December 9, 1998). <http://www2.ohchr.org/english/law/bodyprinciples.htm>.
- UN General Assembly, *Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, Resolution 37/194 (December 18, 1982). <http://www2.ohchr.org/english/law/medicalethics.htm>.
- World Health Organization, *Declaration of Alma-Ata* (September 6-12, 1978). [www.who.int/publications/almaata\\_declaration\\_en.pdf](http://www.who.int/publications/almaata_declaration_en.pdf).
- World Medical Association, *Declaration of Helsinki—Ethical Principles for Medical Research Involving Human Subjects* (June, 1964). [www.wma.net/en/30publications/10policies/b3/index.html](http://www.wma.net/en/30publications/10policies/b3/index.html).
- World Medical Association, *Declaration of Lisbon on the Rights of the Patient* (September/October, 1981). [www.wma.net/en/30publications/10policies/l4/](http://www.wma.net/en/30publications/10policies/l4/).



- World Medical Association, *Declaration on Medical Care for Refugees* (October, 1998). [www.wma.net/en/30publications/10policies/m10/](http://www.wma.net/en/30publications/10policies/m10/).
- World Medical Association, *Regulations in Times of Armed Conflict and other Situations of Violence* (October, 1956). [www.wma.net/en/30publications/10policies/a20/](http://www.wma.net/en/30publications/10policies/a20/).

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## B. Regional Instruments

- Active Citizen Network, *European Charter of Patients' Rights* (2002). [www.eesc.europa.eu/self-and-core-ulation/documents/codes/private/085-private-act.pdf](http://www.eesc.europa.eu/self-and-core-ulation/documents/codes/private/085-private-act.pdf).
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- Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* (1997). <http://conventions.coe.int/Treaty/EN/Treaties/Html/164.htm>.
- Council of Europe, *Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data*, C.E.T.S. No. 108 (entered into force January 28, 1981). <http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=108&CL=ENG>.
- WHO: Regional Office for Europe, *A Declaration on the Promotion of Patients' Rights in Europe* (March, 1994). [www.who.int/genomics/public/eu\\_declaration1994.pdf](http://www.who.int/genomics/public/eu_declaration1994.pdf).

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## C. General Resources

- Active Citizenship Network, *Patients' Rights in Europe: A Citizens' Report* (March 2005). [http://archive.oxha.org/knowledge/publications/oxha\\_dialogue\\_patient\\_rights.pdf](http://archive.oxha.org/knowledge/publications/oxha_dialogue_patient_rights.pdf).
- Beletsky L et al, *Advancing human rights in patient care: the law in seven transitional countries* (2013). Open Society Foundations. [http://iris.lib.neu.edu/slaw\\_fac\\_pubs/244/](http://iris.lib.neu.edu/slaw_fac_pubs/244/).
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- Lines R, "The right to health of prisoners in international human rights law," *International Journal of Prisoner Health*, 4 No. 1 (March 2008): 3-53. [www.ahrn.net/library\\_upload/uploadfile/file3102.pdf](http://www.ahrn.net/library_upload/uploadfile/file3102.pdf).
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- Open Society Institute: Public Health Program, *Observance of the Rights of Injecting Drug Users in the Public Health Care System* (2008).

- UNESCO, *Bioethics Core Curriculum: Casebook on Human Dignity and Human Rights* (2011). <http://cop.health-rights.org/files/d/1/d1fo32879b04e71e9a475d4c7adfaa68.pdf>.  
No. 1: Casebook on Human Dignity and Human Rights. <http://unesdoc.unesco.org/images/0019/001923/192371e.pdf>.  
No. 2: Casebook on Benefit & Harm. <http://unesdoc.unesco.org/images/0019/001923/192370e.pdf>.
- UNODC, *Handbook on Prisoners with special needs* (2009). [www.unodc.org/documents/justice-and-prison-reform/Prisoners-with-special-needs.pdf](http://www.unodc.org/documents/justice-and-prison-reform/Prisoners-with-special-needs.pdf).

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## D. Health Workers and Human Rights

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- Physicians for Human Rights: [physiciansforhumanrights.org/](http://physiciansforhumanrights.org/)

## 6. WHAT ARE THE KEY TERMS RELATED TO PATIENT CARE AND HUMAN RIGHTS?

### A

#### ***Ambulatory care***

Medical care, including diagnosis, observation, treatment, and rehabilitation, provided on an outpatient basis.

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### D

#### ***Dual loyalty***

Role conflict between professional duties to a patient and obligations to the interests of a third party such as an employer, insurer, or the state. The conflict may be express or implied, real or perceived.

---

### E

#### ***Essential medicines***

Medicines that satisfy the priority health care needs of the population. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.

---

### H

#### ***Health***

Complete physical, mental, and social well-being, rather than merely the absence of disease or infirmity (World Health Organization).

#### ***Health care or patient care (see also Patient care)***

1. The prevention, treatment, and management of illness and the preservation of mental and physical well-being through the services offered by the medical, nursing, and allied health professions. This definition and similar ones sometimes are given for “*patient care*” as well. The World Health Organization states that this embraces all the goods and services designed to promote health, including preventive, curative, and palliative interventions, whether directed to individuals or populations.
2. Any type of services provided by professionals or paraprofessionals with an impact on health status (European Observatory on Health Systems and Policy online glossary).
3. Medical, nursing, or allied services dispensed by health care providers and health care establishments. (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994). *See also* “patient care.”

#### ***Health care facility***

Any health care institution such as a hospital, clinic, primary care center. May also be referred to as a medical facility.

#### ***Health care professional***

Physicians, nurses, pharmacists, dentists, midwives, physician assistants, dieticians, paramedics, psychologists, therapists, or other health professionals.

***Health care system***

The organized provision of health care services.

***Human rights in patient care***

Concept that brings together the rights of both patients and health care providers and refers to the application of general human rights principles to all stakeholders in the delivery of health care. It encompasses all rights recognized under international law that are relevant to the provision of health services.

---

**I**

***Individual rights in patient care***

Rights that, when made operation, can be made enforceable on behalf of an individual patient. Individual rights in patient care are more readily expressed in absolute terms than are social rights in health care (Declaration on the Promotion of Patients' Rights in Europe, World Health Organization, 1994). See also "social rights in health care" and "patients' rights."

***Informed consent***

A legal condition in which a person can be said to agree to a course of action based upon an appreciation and understanding of the facts and implications. The individual needs to be in possession of relevant facts and the ability to reason.

***Informed consent in the health care context***

A process by which a patient participates in health care choices. A patient must be provided with adequate and understandable information on matters such as the treatment's purpose, alternative treatments, risks, and side-effects.

***Inpatient***

A patient whose care requires a stay in a hospital or hospice facility for at least one night.

---

**M**

***Medical intervention***

Any examination, treatment, or other act having preventive, diagnostic therapeutic, or rehabilitative aims and which is carried out by a physician or other health care provider (Declaration on the Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

---

**N**

***Neglected diseases***

Diseases that almost exclusively affect underprivileged rural communities in low-income countries; such diseases generally receive inadequate attention and resources.

---

**O**

***Outpatient***

Patient receiving treatment without spending any nights at a health care institution.

## **P**

### ***Patient***

A user of health care services, whether healthy or sick (Declaration on the Promotion of Patients' Rights in Europe, WHO, Amsterdam 1994).

A person in contact with the health system, seeking attention for a health condition (European Observatory on Health Systems and Policies).

### ***Patient autonomy***

A patient's right to make decisions about his or her medical care. Providers can educate and inform patients, but cannot make decisions for them.

### ***Patient care (see also Health care)***

The services rendered by members of the health professions or non-professionals under their supervision for the benefit of the patient. Similar definitions often are provided for the term "health care."

### ***Patient-centered care***

Doctrine recognizing the provision of health services as a partnership among health care providers and patients and their families. Decisions about medical treatments must respect patients' wants, needs, preferences, and values.

### ***Patient confidentiality***

Doctrine holding that the physician has the duty to maintain patient confidences. This is to allow patients to make full and frank disclosure to their physician, enabling appropriate treatment and diagnosis.

### ***Patient mobility***

Concept describing patient movement beyond their catchment area or area of residence to access health care; mobility can take place within the same country or between countries.

### ***Patient responsibility***

A doctrine recognizing the doctor/patient relationship as a partnership with each side assuming certain obligations. Patient responsibilities include communicating openly with the physician or provider, participating in decisions about diagnostic and treatment recommendations, and complying with the agreed-upon treatment program.

### ***Patients' rights***

Set of rights calling for government and health care provider accountability in the provision of quality health services. Associated with a movement empowering patients, particularly in countries where patients are assuming a greater share of health care costs and thus expect to have their rights as "consumers" respected.

A set of rights, responsibilities, and duties under which individuals seek and receive health care services (European Observatory on Health Systems and Policy online glossary).

### ***Patient safety***

Freedom from accidental injury caused by medical care or medical errors (Institute of Medicine).



***Primary health care***

General health services available in the community near places where people live and work; the first level of contact individuals and families have with the health system.

***Public health***

Collective actions of a society to ensure conditions in which people can be healthy (Institute of Medicine).

---

**S**

***Secondary health care***

General health services available in hospitals.

***Social Rights in Health Care***

Category of rights that relate to the societal obligation undertaken or otherwise enforced by government and other public or private bodies to make a reasonable provision of health care for the whole population. These rights also relate to the equal access to health care for all those living in a country or other geopolitical, cultural, social, or psychological. Social rights in health care are enjoyed collectively (Declaration on the Promotion of Patients' Rights in Europe, World Health Organization, 1994). *See also* "individual rights in patient care."

---

**T**

***Terminal care***

Care given to a patient when it is no longer possible to improve the fatal prognosis of his or her illness/condition with available treatment methods, as well as care at the approach of death (Declaration on the Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

***Tertiary health care***

Specialized health services available in hospitals.

# CHAPTER 2



## HIV, AIDS AND HUMAN RIGHTS

“ The face of HIV has always been the face of our failure to protect human rights. ”

— Navi Pillay, UN High Commissioner for Human Rights – July 23, 2012

## **Health and Human Rights Resource Guide**

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Cover photograph courtesy of Sven Torfinn – Panos, Open Society Foundations, “William conducts a sensitization workshop about the rights of people living with HIV in Gayaza, Uganda.”

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# INTRODUCTION

This chapter will introduce you to key issues and resources in HIV, AIDS, and human rights. In addition, this chapter will help you understand why, more now than ever, HIV and AIDS must be understood and approached as a human rights issue.

The chapter is organized into six sections that answer the following questions. Some of these issues are also addressed in Chapter 3 on Tuberculosis and Human Rights, Chapter 4 on Harm Reduction and Human Rights, Chapter 5 on Palliative Care and Human Rights, and Chapter 8 on LGBTI, Health and Human Rights.

1. How are HIV and AIDS a human rights issue?
2. What are the most relevant international and regional human rights standards related to HIV and AIDS?
3. What is a human rights-based approach to advocacy, litigation, and programming?
4. What are some examples of effective human rights-based work in the area of HIV and AIDS?
5. Where can I find additional resources on HIV, AIDS, and human rights?
6. What are some of the key terms related to HIV, AIDS, and human rights?

# I. HOW ARE HIV AND AIDS A HUMAN RIGHTS ISSUE?

## What are HIV and AIDS?

### What do the acronyms HIV and AIDS stand for?<sup>1</sup>

“HIV” stands for human immunodeficiency virus, which is a virus that affects the human immune system. It results in a deterioration of the immune system, causing an individual to become more vulnerable to other infections. “AIDS” stands for acquired immunodeficiency syndrome, which is an advanced stage of HIV defined by the demonstration of certain symptoms, infections, and cancers. An individual with HIV infection may not have developed any of the illnesses that constitute AIDS and the terms should be kept distinct.<sup>2</sup> As UNAIDS notes:

*The expression HIV/AIDS should be avoided whenever possible because it can cause confusion. Most people with HIV do not have AIDS. The expression ‘HIV/AIDS prevention’ is even more unacceptable because HIV prevention entails correct and consistent condom use, use of sterile injecting equipment, changes in social norms, etc., whereas AIDS prevention entails cotrimoxazole, good nutrition, isoniazid prophylaxis (INH), etc.<sup>3</sup>*

There is currently no cure for AIDS. However, people living with HIV can live healthy and productive lives with antiretroviral therapy.<sup>4</sup>

- 
- 1 For basic information on HIV/AIDS, please see the following resources: UNAIDS, *Fast Facts about HIV*. [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/factsheet/2008/20080519\\_fastfacts\\_hiv\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/factsheet/2008/20080519_fastfacts_hiv_en.pdf); Center for Disease Control, *Basic Information about HIV and AIDS*. [www.cdc.gov/ncphi/diss/nndss/print/aidscurrent.htm](http://www.cdc.gov/ncphi/diss/nndss/print/aidscurrent.htm); World Health Organization (WHO), *HIV/AIDS: Fact Sheet No. 360* (July 2012). [www.who.int/mediacentre/factsheets/fs360/en/index.html](http://www.who.int/mediacentre/factsheets/fs360/en/index.html).
  - 2 UNESCO, *UNESCO Guidelines on Language and Content in HIV- and AIDS -Related Materials* (October 2006). <http://unesdoc.unesco.org/imag-es/0014/001447/144725e.pdf>.
  - 3 UNAIDS, *Terminology Guidelines* (October 2011). [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118\\_terminology-guidelines\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf).
  - 4 World Health Organization (WHO), *HIV/AIDS: Fact Sheet No. 360* (July 2012). [www.who.int/mediacentre/factsheets/fs360/en/index.html](http://www.who.int/mediacentre/factsheets/fs360/en/index.html).

## How is HIV spread?<sup>5</sup>

HIV can be transmitted through unprotected and close contact with certain body fluids, such as blood, semen, breast milk, and vaginal secretions from infected individuals. However, transmission is not possible through air or water, shaking hands, kissing, saliva, tears, or mosquitoes. Common routes of transmission include:

- Unprotected vaginal or anal sex with an HIV-positive partner. The risk of contracting HIV from sexual encounters increases if the person has other sexually transmitted infections (STIs) and if the male is uncircumcised.<sup>6</sup> Unprotected anal sex has a higher risk factor than vaginal sex, and unprotected receptive anal sex has a higher risk factor than unprotected insertive anal sex.<sup>7</sup> Transmission can, in some instances with specific conditions, occur through oral sex.
- Passage from an HIV-positive mother to a child during pregnancy, birth, or breastfeeding.
- Sharing contaminated equipment used for injection drug use, including needles, syringes, and wash water.

## How are HIV and AIDS treated?

Antiretroviral therapy (ART) is “the combination of at least three antiretroviral drugs to maximally suppress the HIV virus and stop the progression of the HIV disease.”<sup>8</sup> ART is effective both as life-saving treatment and as protection against HIV/AIDS.<sup>9</sup> According to the Global Commission on HIV and the Law, “Legal strategies, together with global advocacy and generic [drugs], resulted in a 22-fold increase in ART access between 2001 and 2010.” Nevertheless, coverage remains unequal, and in 2011, just 54% of people indicated for ART in low- and middle-income countries received treatment. Globally, just 28% of children in need of treatment received ART.<sup>10</sup> Although there is not yet universal access in many countries, treatment has been successful in extending life expectancy, decreasing HIV transmission,<sup>11</sup> and promoting community activism and empowerment around HIV.<sup>12</sup>

5 More detailed information on transmission is available from the Center for Disease Control, *Basic Information about HIV and AIDS*. [www.cdc.gov/ncphi/diss/nndss/print/aidscurrent.htm](http://www.cdc.gov/ncphi/diss/nndss/print/aidscurrent.htm); Center for Disease Control, *HIV Transmission*. [www.cdc.gov/hiv/resources/qa/transmission.htm](http://www.cdc.gov/hiv/resources/qa/transmission.htm); and World Health Organization, *HIV/AIDS: Fact Sheet No. 360* (July 2012). [www.who.int/mediacentre/factsheets/fs360/en/index.html](http://www.who.int/mediacentre/factsheets/fs360/en/index.html).

6 Canning D, “The Economics of HIV/AIDS in Low-Income Countries: The Case for Prevention,” *Journal of Economic Perspectives* 20 (2006): 121. <http://pubs.aeaweb.org/doi/pdfplus/10.1257/jep.20.3.121>.

7 Center for Disease Control, “Basic Information about HIV and AIDS.” <http://www.cdc.gov/hiv/topics/basic/>.

8 WHO, “HIV/AIDS: Antiretroviral Therapy.” [www.who.int/hiv/topics/treatment/en/](http://www.who.int/hiv/topics/treatment/en/).

9 Ibid.

10 UNAIDS, *Global AIDS epidemic facts and figures*, Fact Sheet (July 18, 2012). [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_FactSheet_Global_en.pdf).

11 Tanser et al, “High Coverage of ART Associated with Decline in Risk of HIV Acquisition in Rural KwaZulu-Natal, South Africa,” *Science* (2013). <http://www.sciencemag.org/content/339/6122/966.short>; Bor J et al, “Increases in Adult Life Expectancy in Rural South Africa: Valuing the Scale-Up of HIV Treatment,” 339, 961 *Science* (2013). <http://www.sciencemag.org.ezp-prod1.hul.harvard.edu/content/339/6122/961.full.pdf>.

12 Robins, S. 2006. “From ‘Rights’ to ‘Ritual’”: AIDS Activism in South Africa.” *American Anthropologist* 108(2):312-323. <http://onlinelibrary.wiley.com.ezp-prod1.hul.harvard.edu/doi/10.1525/aa.2006.108.2.312/pdf>.



## How is HIV a global epidemic?

The UN General Assembly notes that the HIV epidemic constitutes “an unprecedented human catastrophe inflicting immense suffering on countries, communities and families around the world.”<sup>13</sup> More than 30 million people have died of AIDS<sup>14</sup> and there are approximately 34.2 million people living with HIV today. Each year, some 2.5 million people become infected with HIV and around 1.7 million people die of AIDS-related causes, mostly in low- and middle-income countries.<sup>15</sup> Over 16 million children have been orphaned because of AIDS.<sup>16</sup> In the three decades since HIV was first reported, global infection and death rates have declined due to improved access to antiretroviral therapy, which increases life expectancy and reduces the likelihood of transmission. These gains, however, are fragile. HIV and AIDS continue to pose “formidable challenges to the development, progress and stability”<sup>17</sup> of human society and must remain a global priority.<sup>18</sup>

## What is the connection between HIV, AIDS, and tuberculosis?

Tuberculosis (TB), a disease caused by the *Mycobacterium tuberculosis* bacterium that attacks the lungs, is the leading cause of death for people with HIV worldwide.<sup>19</sup> HIV compromises the immune system and thus increases the likelihood of TB infection, progression, and relapse. People living with HIV are estimated to have between 20-37 times greater risk of developing TB than those not living with HIV. In 2009, 1.2 million (13%) of the 9.4 million new cases of TB were among people living with HIV, and 400,000 (24%) of the 1.7 million people who died from TB were living with HIV.<sup>20</sup> It is estimated that one-third of the 40 million people living with HIV worldwide are co-infected with TB.

Unlike AIDS, however, TB can be cured. Studies show that anti-TB drugs can prolong the lives of people living with HIV by at least two years. Therefore, offering TB tests and treatment to people with HIV—and vice versa—greatly increases the manageability of both diseases; indeed, due in large part to the scale-up of joint HIV and TB services, TB deaths in people living with HIV declined by 10% between 2009 and 2010.<sup>21</sup>

Inadequate and inconsistent treatment practices, on the other hand, can cause drug-resistant strains of TB. Multi-drug resistant tuberculosis (MDR-TB) is difficult and costly to treat and can be fatal. The emergence of MDR-TB poses a grave threat not only to people with TB, but to overall progress in the global response to HIV and AIDS.

For more information on TB and health and human rights, please see Chapter 3.

13 UN General Assembly, *Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS*, A/RES/65/277 (June 10, 2011). [www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610\\_UN\\_A-RES-65-277\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_UN_A-RES-65-277_en.pdf).

14 Ibid.

15 UNAIDS, *Global AIDS epidemic facts and figures* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

16 UN General Assembly, *Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS*, A/RES/65/277 (June 10, 2011). [www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610\\_UN\\_A-RES-65-277\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_UN_A-RES-65-277_en.pdf).

17 Ibid.

18 UN Office of the High Commissioner for Human Rights, “HIV/AIDS and Human Rights.” [www.ohchr.org/EN/Issues/HIV/Pages/HIVIndex.aspx](http://www.ohchr.org/EN/Issues/HIV/Pages/HIVIndex.aspx).

19 The Henry J. Kaiser Family Foundation, *US Global Health Policy Fact Sheet: The Global HIV/AIDS Epidemic* (July 2012). [www.kff.org/hiv/aids/upload/3030-17.pdf](http://www.kff.org/hiv/aids/upload/3030-17.pdf).

20 WHO, “The Three I’s for HIV/TB.” [www.who.int/hiv/topics/tb/3is/en/index.html](http://www.who.int/hiv/topics/tb/3is/en/index.html).

21 Kaiser Family Foundation, *US Global Health Policy Fact Sheet: The Global HIV/AIDS Epidemic* (July 2012). [www.kff.org/hiv/aids/upload/3030-17.pdf](http://www.kff.org/hiv/aids/upload/3030-17.pdf).

## How are HIV and AIDS a human rights issue?

Human rights and HIV are inextricably linked. As the Inter-Parliamentary Union's (IPU) *Handbook for Legislators on HIV/AIDS, Law and Human Rights* notes:

*A lack of respect for human rights fuels the spread, and exacerbates the impact, of the disease. At the same time, HIV undermines progress in the realization of human rights. This link is apparent in the disproportionate incidence and spread of the disease among key populations at higher risk, and particularly those living in poverty. It is also apparent in the fact that the overwhelming burden of the epidemic today is borne by low- and middle-income countries. AIDS and poverty are now mutually reinforcing negative forces in many of these countries.*<sup>22</sup>

Human rights are relevant to the response to HIV in at least three ways. First, lack of human rights protection creates vulnerability to HIV,<sup>23</sup> particularly among marginalized and underserved groups such as women, children, and young persons; sex workers; people who use drugs; migrants; men who have sex with men (MSM); transgendered persons; and prisoners.<sup>24</sup> The IPU states:

*[These groups] are more vulnerable to contracting HIV because they are unable to realize their civil, political, economic, social and cultural rights. For example, individuals who are denied the right to freedom of association and access to information may be precluded from discussing issues related to HIV, participating in AIDS service organizations and self-help groups, and taking other preventive measures to protect themselves from HIV. Women, and particularly young women, are more vulnerable to infection if they lack access to information, education and services necessary to ensure sexual and reproductive health and prevention of infection. The unequal status of women also means that their capacity to negotiate in the context of sexual activity is severely undermined. People living in poverty often are unable to access HIV care and treatment, including antiretrovirals.*<sup>25</sup>

Second, lack of human rights protection fuels stigma, discrimination, and violence against persons living with and affected by HIV.<sup>26</sup> These harmful attitudes and practices are rooted in a lack of understanding of HIV, misconceptions about how HIV is transmitted,<sup>27</sup> and “fears and prejudices surrounding sex, blood, disease, and death—as well as the perception that HIV is related to ‘deviant’ or ‘immoral’ behaviors such as sex outside marriage, sex between men, and drug use.”<sup>28</sup> The IPU notes:

22 Inter-Parliamentary Union (IPU), *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007), [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

23 UNAIDS and the UN Office for the High Commissioner for Human Rights, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

24 Ibid. See also Piot P, Greener R, Russell S, “Squaring the Circle: AIDS, Poverty, and Human Development,” *PLOS Medicine* 4, no. 10 (2007): e314. [www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0040314](http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0040314), and World Health Organization, *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector*, Progress Report 2010 (2010). [http://whqlibdoc.who.int/publications/2010/9789241500395\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241500395_eng.pdf).

25 Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

26 Ibid.

27 UNAIDS, *HIV – Related Stigma, Discrimination, and Human Rights Violations: Case Studies of Successful Program* (April 2005). [http://data.unaids.org/publications/irc-pubo6/jc999-humrightsviol\\_en.pdf](http://data.unaids.org/publications/irc-pubo6/jc999-humrightsviol_en.pdf).

28 Open Society Institute, *10 Reasons Why Human Rights Should Occupy the Centre of the Global AIDS Struggle* (2009). [www.hivhumanrightsnow.org](http://www.hivhumanrightsnow.org).

*The rights of people living with HIV often are violated because of their presumed or known HIV-positive status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigmatization and discrimination may obstruct their access to treatment and may affect their employment, housing and other rights. This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourage individuals infected with, and affected by, HIV from contacting health and social services. The result is that those most needing information, education and counselling will not benefit even where such services are available<sup>29</sup>*

Third, lack of human rights protection impedes effective national responses to HIV.<sup>30</sup> Discriminatory, coercive, and punitive approaches to HIV increase vulnerability to infection and worsen the impact of the epidemic on individuals, families, communities and countries.<sup>31</sup> Examples include:

- Ideologically driven restrictions on information about HIV prevention, including safe sex and condom use;
- Criminalization of groups at higher risk of infection, such as men who have sex with men, persons who inject drugs, and sex workers;
- Criminalization of “reckless” or “negligent” HIV exposure or transmission;
- HIV testing without informed consent;
- Limited access to harm reduction measures, such as needle and syringe programs and opioid substitution therapy;
- Limited access to opioid medications for palliative care; and
- HIV-related immigration restrictions on entry, stay, and residence.<sup>32</sup>

These measures deter people from coming forward for HIV services and inhibit the ability of organizations to reach vulnerable and at risk groups.<sup>33</sup> Human rights are thus necessary to achieving universal access to comprehensive prevention, treatment and care; to meeting the rights and needs of the most vulnerable and worst affected populations; and to ensuring voluntary, informed and evidence-based policies, programs and practices.<sup>34</sup> The following are some examples of key human rights issues related to HIV.

29 Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

30 Ibid.

31 UNAIDS, *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses* (2012). [http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_May2012.pdf).

32 Ibid.

33 Ibid. See also Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007), [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

34 Open Society Foundations, *10 Reasons Why Human Rights Should Occupy the Centre of the Global AIDS Struggle* (2009). [www.hivhumanrightsnow.org/vs3\\_korax.net/downloads/nmte\\_20090923\\_o.pdf](http://www.hivhumanrightsnow.org/vs3_korax.net/downloads/nmte_20090923_o.pdf).

## HIV disproportionately affects persons living in developing countries and persons living in poverty.

HIV is deeply rooted in social, economic, and gender inequalities.<sup>35</sup> The burden of the epidemic is disproportionately carried by persons in developing countries. Sub-Saharan Africa remains the worst-affected region, with 69% of all persons living with HIV and 70% of all HIV-related deaths. The Caribbean region has the highest HIV prevalence outside of sub-Saharan Africa and the number of new HIV infections is increasing in Eastern Europe, Central Asia, North Africa, the Middle East, and parts of Asia and the Pacific.<sup>36</sup> The disparate burden of HIV across countries and communities requires “an exceptional and comprehensive global response that takes into account the fact that the spread of HIV is often a consequence and cause of poverty.”<sup>37</sup>

Poverty creates social and legal environments that increase the risk of infection, sickness, and death. Underlying factors include malnutrition, poor health, barriers to accessing health care and other services, and reduced capacity to participate in HIV prevention and care.<sup>38</sup> Poverty increases vulnerability to HIV—even as HIV increases vulnerability to poverty. According to Piot et al.:

*AIDS kills people in the prime of their working and parenting lives, with a devastating effect on the lives and livelihoods of affected households. Incomes shrink when employed household members become sick or die, and resources are further depleted by medical and funeral-related costs. The impact on poor households is clearly disproportionate, with many struggling to meet demands for treatment and care.... For example, in India, the financial burden on households living with HIV was 82% of income in the poorest quintile and just over 20% among the richest quintile.... The very poor struggle to afford even heavily subsidized antiretroviral treatment.... Moreover, even if drugs are free, poor families may have insufficient resources to meet basic nutrition needs or the costs of travel to health clinics for care.*<sup>39</sup>

HIV thus imposes the heaviest toll on persons living in poverty, while impeding human development in high-prevalence countries.<sup>40</sup> The Joint United Nations Programme on AIDS (UNAIDS) and the UN Office of the High Commissioner for Human Rights (OHCHR) state:

*Where human rights are not protected, people are more vulnerable to HIV infection. Where the human rights of HIV-positive people are not protected, they suffer stigma and discrimination, become ill, become unable to support themselves and their families, and if not provided treatment, they die. Where rates of HIV prevalence are high and treatment is lacking, whole communities are devastated by the impact of the virus.... HIV has spread to every country in the world and, in the hardest-hit countries, it is undoing most of the development gains of the past 50 years.*<sup>41</sup>

35 Piot P, Greener R, Russell S, “Squaring the Circle: AIDS, Poverty, and Human Development,” *PLOS Medicine* 4, no. 10 (2007): e314. [www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0040314](http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0040314)

36 UNAIDS, *Report on the global AIDS epidemic 2012*, (2012): 8-12. [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120\\_UNAIDS\\_Global\\_Report\\_2012\\_with\\_annexes\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_UNAIDS_Global_Report_2012_with_annexes_en.pdf).

37 UN General Assembly, *Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS*, A/RES/65/277 (Jun. 10, 2011). [www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610\\_UN\\_A-RES-65-277\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_UN_A-RES-65-277_en.pdf).

38 Ibid. See also Drimie S, “The Impact of HIV/AIDS on rural households and land issues in Southern and Eastern Africa,” Background Paper, (Food and Agricultural Organization, Sub-Regional Office for Southern and Eastern Africa, 2002). [ftp://ftp.fao.org/docrep/nonfao/ad696e/ad696e00.pdf](http://ftp.fao.org/docrep/nonfao/ad696e/ad696e00.pdf).

39 Piot P, Greener R, Russell S, “Squaring the Circle: AIDS, Poverty, and Human Development,” *PLOS Medicine* 4, no. 10 (2007): e314. [www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0040314](http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0040314)

40 Ibid. See also Drimie S, “The Impact of HIV/AIDS on rural households and land issues in Southern and Eastern Africa,” Background Paper, (Food and Agricultural Organization, Sub-Regional Office for Southern and Eastern Africa, 2002). [ftp://ftp.fao.org/docrep/nonfao/ad696e/ad696e00.pdf](http://ftp.fao.org/docrep/nonfao/ad696e/ad696e00.pdf).

41 UNAIDS and UN Office of the High Commissioner for Human Rights (OHCHR), *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

## Stigma, discrimination, and violence violate the human rights of people living with and affected by HIV.

Many countries have yet to significantly address the HIV-related human rights abuses of their citizens. As a result, stigma and discrimination remain pervasive; they are the primary drivers of the HIV epidemic and the main obstacles to effective public action. UN Secretary-General Ban Ki-Moon notes:

*[Stigma] is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world.<sup>42</sup>*

UNAIDS defines stigma as the process of devaluing an individual based on certain attributes deemed discrediting or unworthy by others. Discrimination, in turn, occurs when stigma is acted on and consists of the actions or behaviors directed against stigmatized individuals.<sup>43</sup> In the context of HIV, discrimination can increase vulnerability to infection, particularly among legally and socially marginalized groups such as sex workers, people who use drugs, men who have sex with men, and prisoners. According to UNAIDS and OHCHR:

*Discrimination often prevents them from having access to HIV prevention information, modalities (condoms and clean injecting equipment) and services (for sexually transmitted infections and tuberculosis). This, as well as risk-taking behaviour, makes them highly vulnerable to HIV infection.<sup>44</sup>*

At the same time, discrimination can also relate to HIV status itself. People with actual or presumed HIV-positive status may be denied the right to health care, employment, education, and freedom of movement, among other rights.<sup>45</sup>

42 Ki-Moon B, *The Stigma Factor*, The Washington Times, (Aug. 6, 2008). [www.washingtontimes.com/news/2008/aug/06/the-stigma-factor/](http://www.washingtontimes.com/news/2008/aug/06/the-stigma-factor/).

43 UNAIDS, *HIV – Related Stigma, Discrimination, and Human Rights Violations: Case Studies of Successful Program* (April 2005). [http://data.unaids.org/publications/irc-pubo6/jc999-humrightsviol\\_en.pdf](http://data.unaids.org/publications/irc-pubo6/jc999-humrightsviol_en.pdf)

44 UNAIDS and the UN Office of the High Commissioner for Human Rights, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

45 Ibid

For example, all people have the right to decent work and their HIV status should not influence their ability to find and keep employment. Yet people living with HIV often face stigma and discrimination in the workplace.<sup>46</sup> This can affect recruitment, salary levels, training opportunities, labor protection, social insurance, welfare, and dismissal.<sup>47</sup> The Global Network of People Living with HIV found that up to 45% of survey respondents in Nigeria had lost their jobs or their source of income during the previous 12 months, and up to 27% were refused the opportunity to work as a result of their HIV status.<sup>48</sup> To address HIV and AIDs discrimination in the workplace, the International Labour Organization released a recommendation on HIV/AIDs and work in 2001 (“The Code”) and a standard in 2010 to bolster implementation of the Code at the country level.<sup>49</sup> The Code guidelines are:<sup>50</sup>

- No mandatory HIV testing for workers under any circumstances or for any purpose.
- No denial of job opportunities for workers with HIV in any area of work.
- No discrimination of workers such as denial of promotions or shifting job responsibilities.
- Guaranteed confidentiality with regard to HIV status in the workplace.

Discrimination on account of HIV status can contribute to poverty, poor health, and further marginalization. For example, lack of employment security contributes to worse health outcomes, since employment status can determine access to health care and social benefits.<sup>51</sup> When people living with HIV cannot find or keep employment, the loss of income and simultaneous loss of benefits exacerbates poverty and makes adherence to HIV treatment more difficult.

To combat HIV-related stigma manifest in social and legal barriers, countries should enact formal laws that prohibit discrimination on the basis of HIV status for purposes of employment, education, social and health care services, or immigration and asylum applications. The Commission on HIV and the Law reports that of 168 reviewed countries, 123 reported that they had laws that prohibited HIV-related discrimination.<sup>52</sup> However, the Office of the High Commission on Human Rights cautions that many of these anti-discrimination laws may not be effective:

46 Global Network of People Living with HIV (GNP+), *Stigma and Discrimination at Work: Findings from the People Living with HIV Stigma Index*, Evidence Brief, (2012). [www.gnpplus.net/images/stories/Rights\\_and\\_stigma/SI\\_WorkBriefing\\_Online.pdf](http://www.gnpplus.net/images/stories/Rights_and_stigma/SI_WorkBriefing_Online.pdf).

47 National Center for AIDS/STD Control and Prevention, China CDC & International Labour Office for China and Mongolia, *HIV and AIDS Related Employment Discrimination in China*. [www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---sro-bangkok/documents/publication/wcms\\_150386.pdf](http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---sro-bangkok/documents/publication/wcms_150386.pdf).

48 International Labour Organization (ILO), *HIV still a major obstacle to employment security* (July 24, 2012). [www.ilo.org/global/about-the-ilo/newsroom/news/WCMS\\_185826/lang-en/index.htm](http://www.ilo.org/global/about-the-ilo/newsroom/news/WCMS_185826/lang-en/index.htm).

49 International Labour Organization, *Recommendation concerning HIV and AIDS and the World of Work* (No. 200) (2010), [www.ilo.org/aid/WCMS\\_142706/lang-en/index.htm](http://www.ilo.org/aid/WCMS_142706/lang-en/index.htm). Available in many languages. See also, ILO, *Code of Practice on HIV/AIDS and the World of Work*, [www.ilo.org/aid/Publications/WCMS\\_113783/lang-en/index.htm](http://www.ilo.org/aid/Publications/WCMS_113783/lang-en/index.htm).

50 National Center for AIDS/STD Control and Prevention, China CDC & International Labour Office for China and Mongolia, *HIV and AIDS Related Employment Discrimination in China*. [www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---sro-bangkok/documents/publication/wcms\\_150386.pdf](http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---sro-bangkok/documents/publication/wcms_150386.pdf).

51 Rueda SI, “Labour Force Participation and health-related quality of life in people living with HIV”, *AIDS Behavior* 16, no. 8 (2012):2350-60. [www.ncbi.nlm.nih.gov/pubmed/22814570](http://www.ncbi.nlm.nih.gov/pubmed/22814570).

52 Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>. The Global Commission on HIV and the Law is an independent body, convened by UNDP on behalf of the program Coordinating Board of the Joint United Nations program on HIV/AIDS (UNAIDS).



*When anti-discrimination provisions are in place, they are often not effectively enforced. Fewer than 60 per cent of countries report having a mechanism to record, document and address cases of HIV-related discrimination. In 2010, the vast majority of countries reported that they addressed stigma and discrimination in their national HIV strategies; however, most countries did not have a budget for activities aimed at responding to HIV-related stigma and discrimination.*<sup>53</sup>

Four organizations have partnered<sup>54</sup> to document the experiences of people living with HIV-related stigma, discrimination, and rights violations by developing an index called “People Living with HIV Stigma Index.”<sup>55</sup> The aim of the index is to “broaden our understanding of the extent and forms of stigma and discrimination faced by people living with HIV in different countries[,]” and to use the data as an advocacy tool.<sup>56</sup> This tool is helpful in understanding and documenting the extent to which discrimination and stigma affect the daily lives of persons living with HIV.

The People Living with HIV Stigma Index demonstrates that stigma and discrimination are widespread. Stigma can lead to social ostracism, loss of income or livelihoods, denial of medical services or poor care within the health sector, loss of marriage and childbearing options, violence and depression/loss of hope (internalized stigma).<sup>57</sup> Discrimination perpetuates the stigma associated with HIV-positive status and hinders HIV prevention and intervention. HIV-related stigma and discrimination make people afraid to seek information and education about prevention methods, to find out their status, to disclose their status—even to family and sexual partners—and to adhere to treatment schedules.<sup>58</sup>

HIV education plays an important role in reducing discrimination and stigma. It is also important to ensure that services are delivered in a manner that changes negative social norms at the population level.<sup>59</sup> For example, there is some evidence that HIV-associated stigma is decreasing in some communities due to high rates of social exposure to people who are receiving ART.<sup>60</sup> Education, outreach, and other mechanisms to reduce social stigma can make people less afraid of HIV, more willing to be tested, to disclose their status, and to seek care when necessary. All these factors contribute to a more open and inclusive environment.<sup>61</sup>

53 United Nations High Commissioner for Human Rights, *The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS)*, A/HRC/19/37 (Dec. 14, 2011). [http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.37\\_en.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.37_en.pdf).

54 The Global Network of People Living with HIV/AIDS (GNP+); The International Community of Women Living with HIV/AIDS (ICW); The International Planned Parenthood Federation (IPPF); and The Joint United Nations Programme on HIV/AIDS (UNAIDS).

55 The People Living with HIV Stigma Index. [www.stigmaindex.org/](http://www.stigmaindex.org/).

56 The People Living with HIV Stigma Index, “User Guide.” [www.stigmaindex.org/9/aims-of-the-index/aims-of-the-index.html](http://www.stigmaindex.org/9/aims-of-the-index/aims-of-the-index.html).

57 AVERT, “HIV and AIDS Stigma and Discrimination.” [www.avert.org/hiv-aids-stigma.htm#contentTable1](http://www.avert.org/hiv-aids-stigma.htm#contentTable1); UNAIDS, *Non-discrimination in HIV responses* (2010). [www.unaids.org/en/media/unaids/contentassets/documents/priorities/20100526\\_non\\_discrimination\\_in\\_hiv\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/priorities/20100526_non_discrimination_in_hiv_en.pdf).

58 UNAIDS and OHCHR, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

59 See, e.g., England R, “The Writing is on the wall for UNAIDS,” *BMJ* 336, no. 7652 (2008). <http://www.ncbi.nlm.nih.gov/ezp-prod1.hul.harvard.edu/pmc/articles/PMC2375992/>; Jewkes R, “Beyond Stigma: social responses to HIV in South Africa,” *The Lancet* 368, no. 9534 (August 2006). <http://www.sciencedirect.com/ezp-prod1.hul.harvard.edu/science/article/pii/S0140673606691307>.

60 Bor J et al, *Social exposure to an antiretroviral treatment programme in rural KwaZulu Natal*, (Africa Centre and University of Kwazulu-Natal, 2011).

61 AVERT, “HIV and AIDS Stigma and Discrimination.” [www.avert.org/hiv-aids-stigma.htm#contentTable1](http://www.avert.org/hiv-aids-stigma.htm#contentTable1).

## Gender inequality, gender-based violence, and the low status of women and girls remain three of the principal drivers of HIV.

Women and girls are disproportionately affected by the HIV epidemic. It is estimated that about 75% of all women living with HIV are in sub-Saharan Africa.<sup>62</sup> HIV remains the “leading cause of death of women of reproductive age”<sup>63</sup> and a leading cause of maternal death.<sup>64</sup> In 2011, approximately 1.2 million women and girls were newly infected with HIV.<sup>65</sup> Young women between 15 to 24 years of age account for 63% of young people living with HIV and have “infection rates twice as high as among men of the same age.”<sup>66</sup> Despite this, “Less than half (46%) of all countries allocate resources for the specific needs of women and girls in their national response to HIV.”<sup>67</sup>

The manifestation of gender inequality in the HIV epidemic extends beyond infection rates. The International Guidelines on HIV/AIDS and Human Rights notes the extensive impact of gender inequality on the HIV epidemic:

*Women’s subordination in the family and in public life is one of the root causes of the rapidly increasing rate of infection among women. Systematic discrimination based on gender also impairs women’s ability to deal with the consequences of their own infection and/or infection in the family, in social, economic and personal terms.*<sup>68</sup>

As the UN Secretary General noted, “Gender inequality affects women’s experience of living with HIV, their ability to cope once infected and their access to HIV and AIDS services, including treatment.”<sup>69</sup> Women’s experiences of living with HIV are further influenced by social and economic gender disparities. For example, women are often care givers, which is complicated if the person they care for contracts HIV or they themselves become HIV infected. Their duties as care givers can become significantly more demanding and complex, compounded by additional economic and social burdens. Also, if women lose their partners to HIV, they may face economic insecurity because of discriminatory employment, inheritance, or property laws. Legal and social empowerment, as well as increased education for women, are both important measures to address the manifest gender disparities that exist in the context of HIV.

62 AVERT, “Women, HIV and AIDS.” [www.avert.org/women-hiv-aids.htm#contentTableo](http://www.avert.org/women-hiv-aids.htm#contentTableo).

63 UNAIDS, *Global AIDS epidemic facts and figures* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

64 Fried S et al, “Integrating interventions on maternal mortality and morbidity and HIV: A human rights-based framework and approach,” *Health and Human Rights* 14, no. 2 (2012). [www.hhrjournal.org/index.php/hhr/article/view/512/776](http://www.hhrjournal.org/index.php/hhr/article/view/512/776).

65 UNAIDS, *Global AIDS epidemic facts and figures* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

66 UNAIDS, *Global AIDS epidemic facts and figures* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

67 UNAIDS, *Report on the global AIDS epidemic 2010* (2010). [www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm).

68 UN Office of the High Commissioner for Human Rights and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version* (2006): 110. [www.ohchr.org/Documents/Issues/HIV/ConsolidatedGuidelinesHIV.pdf](http://www.ohchr.org/Documents/Issues/HIV/ConsolidatedGuidelinesHIV.pdf).

69 UN Commission on the Status of Women, *Report of the Secretary General on women, the girl child and HIV and AIDS*, E/CN.6/2011/7 (Dec. 3, 2010): 2. [www.un.org/womenwatch/daw/csw/csw55/documentation.htm](http://www.un.org/womenwatch/daw/csw/csw55/documentation.htm).



## Gender in the law

Laws and policies can be an important source of empowerment for women in the context of HIV, but they can also be equally discriminatory. Laws can create barriers for women to access health services or HIV treatment itself and to protect themselves from HIV infection. Laws can also harm women by legalizing genital mutilation or denying inheritance and property rights, causing more risk and vulnerability to the social determinants of HIV and its effects.<sup>70</sup> For example, the Global Commission noted that, in 2012, 127 countries did not have laws criminalizing marital rape.<sup>71</sup>

## Economic status

Women are at an increased risk of becoming infected with HIV due to unequal access to resources, including land and income-generating opportunities, as well as economic dependence on men. Unequal access to resources and economic dependence on men increase the probability that women and girls will engage in variety of unsafe sexual behaviors, including transaction sex, coerced sex, earlier sexual debut, and multiple sex partners.<sup>72</sup> Despite initial concerns that women might face greater barrier to ART access, there is no evidence of socio-economic gradients in ART access, with the exception of distance to the nearest clinic.<sup>73</sup> However, a lack of resources can prevent women from accessing necessary health services for prevention, treatment and care.

## Gender-based power imbalances in sexual and reproductive decision-making

Gender-based power imbalances in sexual decision-making put women at increased risk to contract HIV and can have grave consequences for women. The majority of HIV transmissions to women occur during heterosexual intercourse, and women are twice more likely than men to acquire HIV from an infected partner during unprotected heterosexual intercourse.<sup>74</sup> Gender inequality in sexual relationships can range from women not having power to control their sexual relations both in and out of marriage, women who are married to men for whom having multiple partners is encouraged, the genital mutilation of women, and the early or forced marriage of women. Violence against women also puts women at increased risk for HIV and remains a real threat for women worldwide. Gender-based power imbalances also affect women's autonomy and independent decision-making on reproductive issues, including methods of protection against HIV during sexual encounters, methods of contraception, testing for HIV, and treatment and care options.

70 World Bank, *Protecting Women's Land and Property Rights in the Context of AIDS*. <http://siteresources.worldbank.org/INTGENAGRLIVSOUBOOK/Resources/AfricalAP.pdf>.

71 Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

72 What Works for Women and Girls, *Promoting Women's Employment, Income and Livelihood Opportunities*. [www.whatworksforwomen.org/chapters/21-Strengthening-the-Enabling-Environment/sections/63-Promoting-Womens-Employment-Income-and-Livelihood-Opportunities](http://www.whatworksforwomen.org/chapters/21-Strengthening-the-Enabling-Environment/sections/63-Promoting-Womens-Employment-Income-and-Livelihood-Opportunities).

73 Cooke et al, "Population uptake of antiretroviral treatment through primary care in rural South Africa," *BMC Public Health* 10 (2010). <http://www.ncbi.nlm.nih.gov/ezip-prod1.hul.harvard.edu/pmc/articles/PMC3091553/pdf/1471-2458-10-585.pdf>.

74 AVERT, "Women, HIV and AIDS." [www.avert.org/women-hiv-aids.htm#contentTableo](http://www.avert.org/women-hiv-aids.htm#contentTableo).

## The rights and needs of children under the age of 15 are largely ignored in the response to HIV.

An estimated 3.4 million children under 15 are living with HIV today. In 2011, 330,000 new children became infected with HIV—91% of whom live in sub-Saharan Africa—and an additional 230,000 children died of AIDS-related causes.<sup>75</sup> Children and young people are among the worst affected by HIV due to failures to protect their human rights. The UNAIDS and OHCHR *Handbook on HIV and Human Rights for National-Human Rights Institutions* states:

*According to the Convention on the Rights of the Child and its optional protocols, children have many of the rights of adults in addition to particular rights for children that are relevant in relation to HIV and AIDS. Children have the right to freedom from trafficking, prostitution, sexual exploitation and sexual abuse; the right to seek, receive and impart information on HIV; and the right to special protection and assistance if deprived of their family environment. They also have the right to education, the right to health and the right to inherit property. The right to special protection and assistance if deprived of their family environment protects children if they are orphaned by AIDS. And the right of children to be actors in their own development and to express their opinions empowers them to be involved in the design and implementation of HIV-related programmes for children.<sup>76</sup>*

Nevertheless, progress remains unsatisfactory in the prevention, diagnosis, and treatment of HIV in children. Many children affected by HIV experience poverty, homelessness, school drop-out, discrimination, loss of economic and social opportunity, and early death. Countries are not adequately fulfilling their commitments to provide care and support for vulnerable children, including and especially orphans and children living in AIDS-affected families.

### Prevention of mother-to-child transmission of HIV

Preventing mother-to-child transmission of HIV (PMTCT) remains a priority in eliminating HIV in children. More than 90% of HIV-positive children are infected through their mother during pregnancy, labor, delivery, and breastfeeding. Without intervention, there is a 20 to 45% chance that a mother will transmit HIV to her baby.<sup>77</sup> Moreover, without intervention, half of all infected children will die before their second birthday.<sup>78</sup>

Lack of universal access to PMTCT services highlights inequities that result from a failure to protect human rights. The prescribed strategy requires administering antiretrovirals (ARTs) to the mother before birth and during labor, administering ARTs to the baby following birth, and undertaking preventative measures to avoid HIV transmission through breast milk. These methods are successfully applied in high-income countries, where mother-to-child transmission is rare.

75 UNAIDS, *Global AIDS epidemic facts and figures* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

76 UNAIDS and the UN Office of the High Commissioner for Human Rights, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

77 AVERT, "Preventing Mother-to-child Transmission (PMTCT) in Practice." [www.avert.org/pmtct-hiv.htm](http://www.avert.org/pmtct-hiv.htm).

78 UNAIDS, *Children and AIDS: Fifth Stocktaking Report* (2010). [http://www.unicef.org/publications/files/Children\\_and\\_AIDS-Fifth\\_Stocktaking\\_Report\\_2010\\_EN.pdf](http://www.unicef.org/publications/files/Children_and_AIDS-Fifth_Stocktaking_Report_2010_EN.pdf).

Women in resource-poor countries, however, often do not have access to PMTCT services.<sup>79</sup> Despite concerted efforts to address the issue, in 2011 just 57% of the 1.5 million pregnant women living with HIV in low- and middle-income countries received ARTs to avoid transmission to their child.<sup>80</sup> Barriers in resource-poor settings include clinic resources, testing methods, fear and distrust, disclosure and discrimination issues, drug effectiveness, treatment for mothers, feasibility of replacement feeding, and male visits to antenatal clinics. Despite these challenges, effective delivery of PMTCT services has been well documented in resource-limited public health systems.<sup>81</sup>

### Protection, care, and support for children living with or affected by HIV

Many children lack full access to the HIV prevention information, education, and services they are entitled to under international human rights law. They also receive less antiretroviral treatment than adults, with just 28% of those in need receiving treatment,<sup>82</sup> and they have limited access to pediatric formulations of HIV medicines.<sup>83</sup> Moreover, children are highly vulnerable to the impact of AIDS on their family and community environments. An estimated 17.1 million children under 18 have lost one or both parents to AIDS, with around 14.8 million such orphans in sub-Saharan Africa.<sup>84</sup> In some instances, children may be forced to become child heads of their households. Orphans and children living in AIDS-affected households are denied their right to social protection and face higher risks of poverty, abuse, exploitation, discrimination, property-grabbing, school drop-out, and homelessness.<sup>85</sup>

## The rights and needs of young people aged 15 to 24 are largely ignored in the response to HIV.

With 890,000 new infections in 2011, approximately 4.9 million young people are living with HIV—75% of whom are living in sub-Saharan Africa.<sup>86</sup> Young women make up 63% of all young people living with HIV globally; however, in sub-Saharan Africa, young women make up 72% of young people living with HIV. Young women in sub-Saharan Africa are eight times more likely to be living with HIV than their male peers.

Young people still are not receiving adequate education on HIV and they face barriers accessing information. Many youth do not receive adequate sex education, and those who do are often misinformed on HIV prevention and HIV transmission. For example, UNAIDS reports: “Only 24% of young women and 36% of young men responded correctly when asked five questions on HIV prevention and HIV transmission, according to the most recent population based surveys in low- and middle-income countries.”<sup>87</sup>

79 AVERT, “Preventing Mother-to-child Transmission (PMTCT) in Practice.” [www.avert.org/pmtct-hiv.htm](http://www.avert.org/pmtct-hiv.htm).

80 UNAIDS, *Global AIDS epidemic facts and figures* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

81 See, AVERT, “Preventing Mother-to-child Transmission (PMTCT) in Practice.” [www.avert.org/pmtct-hiv.htm](http://www.avert.org/pmtct-hiv.htm).

82 UNAIDS, *Report on the global AIDS epidemic 2012* (2012). [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120\\_UNAIDS\\_Global\\_Report\\_2012\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_UNAIDS_Global_Report_2012_en.pdf).

83 Open Society Foundations, *10 Reasons Why Human Rights Should Occupy the Centre of the Global AIDS Struggle* (2009). [www.hivhumanrightsnow.org](http://www.hivhumanrightsnow.org); UNAIDS and OHCHR, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

84 UNICEF, “Childinfo: Monitoring the Situation of Children and Women.” [www.childinfo.org/hiv\\_aids.html](http://www.childinfo.org/hiv_aids.html).

85 Open Society Foundations, *10 Reasons Why Human Rights Should Occupy the Centre of the Global AIDS Struggle* (2009). [www.hivhumanrightsnow.org](http://www.hivhumanrightsnow.org); UNAIDS and OHCHR, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

86 UNAIDS, *Global AIDS epidemic facts and figures* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

87 Ibid.

Young people also face barriers accessing HIV services, including sexual and reproductive health services, HIV treatment, and harm reduction. These barriers include stigma, discrimination, and restrictive laws and policies.<sup>88</sup> For example, requiring parental approval to receive HIV testing or treatment can be a significant deterrent for youth, running counter to HIV prevention efforts.

In addition to an inability to realize the right to the highest attainable standard of health, young people living with HIV also often face discrimination in accessing the full range of human rights. For example, UNESCO recently released a publication addressing the barriers and discriminatory practices impeding HIV-positive youth from attending school and getting an education.<sup>89</sup> According to the IPU, “Evidence has demonstrated that getting and keeping young people (particularly girls) in school dramatically lowers their vulnerability to HIV.”<sup>90</sup>

## **The most vulnerable and worst affected populations often receive the least attention in national responses to HIV.**

In most countries, men who have sex with men; people who use drugs; sex workers; and prisoners have a higher prevalence of HIV infection than that of the general population because they engage in behaviors that put them at higher risk of becoming infected, and they are among the most marginalized and discriminated-against populations in society. Punitive approaches to drug use, sex work, and homosexuality fuel stigma and hatred against these populations, pushing them further into hiding and away from services to prevent, treat, and mitigate the impact of HIV. At the same time, the resources devoted to HIV prevention, treatment, and care for these populations are not proportional to the HIV prevalence, which represents “a serious mismanagement of resources and a failure to respect fundamental human rights.”<sup>91</sup>

### **Sex workers**

UNAIDS defines sex workers as “consenting female, male, and transgender adults and young people over the age of 18 who receive money or goods in exchange for sexual services, either regularly or occasionally.”<sup>92</sup> Sex workers are particularly vulnerable to HIV because of their multiple sexual partners and inconsistent condom use,<sup>93</sup> discrimination and stigma, criminalization of their work, increased risk of violence, lack of education or information, and barriers to accessing health services. For example, in Rwanda, the prevalence of HIV among female commercial sex workers was 51%, which is 17 times the national average of 3%.<sup>94</sup>

88 Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

89 UNESCO and the Global Network of People Living with HIV, *Positive Learning: Meeting the needs of young people living with HIV (YPLHIV) in the education sector*. <http://unesdoc.unesco.org/images/0021/002164/216485E.pdf>.

90 Inter-Parliamentary Union (IPU), *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007), [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

91 UNAIDS, quoted in Open Society Institute, *10 Reasons Why Human Rights Should Occupy the Centre of the Global AIDS Struggle* (2009). [www.hivhumanrightsnow.org.vs3.korax.net/downloads/nmte\\_20090923\\_o.pdf](http://www.hivhumanrightsnow.org.vs3.korax.net/downloads/nmte_20090923_o.pdf).

92 UNAIDS, *UNAIDS Terminology Guidelines* (Oct. 2011). [www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118\\_terminology-guidelines\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf).

93 AVERT, “Sex Workers and HIV Protection.” [www.avert.org/sex-workers.htm](http://www.avert.org/sex-workers.htm).

94 IRIN News, *Rwanda: Criminalization of sex work hinders HIV prevention efforts* (Nov. 17, 2011). [www.irinnews.org/Report/94231/RWANDA-Criminalization-of-sex-work-hinders-HIV-prevention-efforts](http://www.irinnews.org/Report/94231/RWANDA-Criminalization-of-sex-work-hinders-HIV-prevention-efforts).

Criminalization of sex work creates barriers to accessing HIV prevention and treatment services. More than 100 countries criminalize some aspect of sex work, according to the Global Commission on HIV and the Law.<sup>95</sup> In many countries, including Kenya, Namibia, Russia, South Africa, and the United States, police confiscate condoms from sex workers or use condoms as a justification for arrest, thereby undermining HIV prevention efforts. These practices criminalize condoms and force sex workers to choose between protecting their health or detention.<sup>96</sup>

Sex workers are also vulnerable to violence, which also increases their risk of contracting HIV. Some sex workers face threats and violence from clients, managers, and intimate partners that prevent them from enforcing condom use. Street-based sex workers are at particular risk and may be forced to exchange unpaid and unprotected sex with some police officers in order to prevent arrest, harassment, obtain release from prison or not be deported.<sup>97</sup>

### Men who have sex with men

Men who have sex with men are considered a vulnerable or at-risk population for HIV. This is a diverse group that includes men who identify as gay or bisexual, as well heterosexual men who have sex with men. They are particularly vulnerable to HIV because sex between men can involve anal sex, a practice that, when no protection is used, has a higher risk of HIV transmission than unprotected vaginal sex.<sup>98</sup>

Men who have sex with men are also vulnerable to HIV because of social stigma, discriminatory practices, and criminalization of same-sex conduct. Sex between men is taboo in many cultures and, as a result, HIV prevention campaigns only discuss the risks of heterosexual sex. Some countries deny the existence of homosexuality at all and limit research and funding on the health of this population. There is often little information available about sex between men in these contexts, and this can provide a false impression of limited or no risk.<sup>99</sup>

The criminalization or punishment of same-sex conduct also creates barriers to accessing healthcare and HIV prevention measures, which also contributes to the underlying determinants of health. The UN Special Rapporteur on the right to health notes:

*Various criminal laws exist worldwide that make it an offence for individuals to engage in same-sex conduct, or penalize individuals for their sexual orientation or gender identity. ... Other laws also indirectly prohibit or suppress same-sex conduct, such as anti-debauchery statutes and prohibitions on sex work. Many States also regulate extra-marital sexual conduct through criminal or financial sanctions, which affects individuals who identify as heterosexual but intermittently engage in same-sex conduct.*<sup>100</sup>

95 Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

96 Open Society Foundations, *Criminalizing Condoms: How Policing Practices Put Sex Workers And Hiv Services At Risk In Kenya, Namibia, Russia, South Africa, The United States, And Zimbabwe* (July 2012). [www.Soros.Org/Reports/Criminalizing-Condoms](http://www.Soros.Org/Reports/Criminalizing-Condoms).

97 WHO, *Violence Against Women and HIV/AIDS: Critical Intersection.*, [www.who.int/gender/documents/sexworkers.pdf](http://www.who.int/gender/documents/sexworkers.pdf).

98 Avert, "HIV, AIDS, and Men who have sex with men." [www.avert.org/men-sex-men.htm](http://www.avert.org/men-sex-men.htm).

99 Semugoma P, Nemande S, Baral SD, "The irony of homophobia in Africa," 380, no. 9839 *The Lancet* (July 2012).

100 Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/14/20 (Apr. 27, 2010). <http://www2.ohchr.org/english/bodies/hrcouncil/14session/reports.htm>. Report is on the right to health and criminalization of same-sex conduct and sexual orientation, sex-work and HIV transmission.

Further, “Sanctioned punishment by States reinforces existing prejudices, and legitimizes community violence and police brutality directed at affected individuals.”<sup>101</sup> The Global Commission on HIV and the Law notes that 78 countries criminalize sexual conduct between same sex partners,<sup>102</sup> and it is punishable by death in five of these countries (Iran, Mauritania, Saudi Arabia, Sudan, Yemen, and parts of Nigeria and Somalia).<sup>103</sup>

### Prisoners

Although many prisoners living with HIV contracted their infections before imprisonment, the risk of infection while in prison is high due to high-risk sexual and other behaviors, like sharing needles. High-risk sexual behaviors, including unprotected sex, sexual violence, rape, and coercion, are common in prison and increase prisoners’ vulnerability to HIV.<sup>104</sup> Unsafe drug injection, blood exchange, and the use of non-sterile needles/cutting instruments for tattooing are also common and increase HIV vulnerability. Poor prison conditions, including overcrowding, poor food and nutrition, poor security, and lack of health facilities and staff contribute to the spread of HIV and violate prisoners’ human rights.

Some prisons create separate or alternative sections for HIV-positive prisoners, segregating them from the rest of the prison population. In parts of Russia, prisoners are tested for HIV and those who test positive are imprisoned together, but separated from the general prison population. Two states in the United States, Alabama and South Carolina, continue to segregate prisoners living with HIV. The American Civil Liberties Union and the AIDS Project recently filed a lawsuit calling the practice discriminatory.<sup>105</sup> Their reports highlight additional human rights violations that are consequences from discriminatory segregation.

### People who inject drugs

An estimated 15.9 million people worldwide inject drugs, the majority of whom live in middle- and low-income countries.<sup>106</sup> Drug-dependent people are frequently subjected to laws, policies and practices that violate their human rights. This increases their vulnerability to HIV and HIV-related risk behaviors, negatively affects the delivery of HIV programs and compromises their health, as well as the health of their communities. As a result, people who inject drugs face a disproportionately high risk of infection and injection drug use accounts for an estimated 10% of total HIV infections.<sup>107</sup>

The link between human rights abuses experienced by people who use drugs and vulnerability to HIV infection and barriers to accessing is well-documented. Many violations are related to the criminalization of the status of being a drug user, which can result in the imposition of the death sentence for drug offenses, incarceration of drug-dependent people and abusive law enforcement practices (for example, police harassment, arbitrary detention, ill treatment, and torture). Other violations are related to the abusive treatment of people who inject drugs, such as denial of harm-reduction services (including needle and syringe programs and opioid substitution therapy), discriminatory access to antiretroviral therapy, denial of pain relief and palliative care, and coercion in the guise of treatment for drug dependence.<sup>108</sup> According to the Now More Than Ever Campaign:

<sup>101</sup> Ibid.

<sup>102</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>103</sup> AVERT, “HIV, AIDS, and Men who have sex with men.” [www.avert.org/men-sex-men.htm](http://www.avert.org/men-sex-men.htm).

<sup>104</sup> WHO, *Effectiveness of Interventions to Address HIV in Prisons* (2007). [http://whqlibdoc.who.int/publications/2007/9789241596190\\_eng.pdf](http://whqlibdoc.who.int/publications/2007/9789241596190_eng.pdf).

<sup>105</sup> For the copy of the legal documents, news reports, and blog posts on the case, please see American Civil Liberties Union, *Henderson et al. v. Thomas et al.*, [www.aclu.org/hiv-aids-prisoners-rights/henderson-et-al-v-thomas-et-al](http://www.aclu.org/hiv-aids-prisoners-rights/henderson-et-al-v-thomas-et-al).

<sup>106</sup> Mathers B et al., “The global epidemiology of injecting drug use and HIV among people who inject drugs: A systematic review,” *Lancet* 372, no. 9651 (2008): 1733–1745.

<sup>107</sup> World Health Organization, *HIV/AIDS: Injecting Drug Use*, <http://www.who.int/hiv/topics/idu/en/index.html>.

<sup>108</sup> Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475-485.



*Criminalized populations...are driven from HIV services by discrimination and violence, often at the hands of police officers and judges charged with enforcing sodomy, narcotics and prostitution laws... People who use drugs end up in prison or in a revolving door of ineffective and coercive rehabilitation programs, rarely receiving the services for drug addiction or HIV prevention and treatment they desperately need.*<sup>109</sup>

To effectively address HIV in people who use drugs, there must be greater understanding of human rights violations as core features of risk environments, as barriers to care, and as social determinants of poor health and development. HIV prevention and treatment efforts must address the specific needs and rights of people who inject drugs and promote access to harm prevention services. According to Jurgens et al.:

*Protection of the human rights of people who use drugs therefore is important not only because their rights must be respected, protected, and fulfilled, but also because it is an essential precondition to improving the health of people who use drugs. Rights-based responses to HIV and drug use have had good outcomes where they have been implemented, and they should be replicated in other countries.*<sup>110</sup>

For more detailed information on this topic, please see Chapter 4 on harm reduction and human rights.

## **HIV testing frequently takes place without the full protection of voluntariness, confidentiality, and informed consent.**

HIV testing implicates a broad range of ethical and human rights issues, including the rights to health, education, information, privacy, liberty and security of the person, and non-discrimination and equality before the law.<sup>111</sup> The 2004 UNAIDS/WHO *Policy Statement on HIV Testing* notes:

*The conditions of the ‘3 Cs’, advocated since the HIV test became available in 1984, continue to be underpinning principles for the conduct of HIV testing of individuals. Such testing of individuals must be **confidential**, be accompanied by **counseling**, [and] only be conducted with **informed consent**, meaning that it is both informed and voluntary.*<sup>112</sup>

Under international human rights law, individuals have a right to information and education, which entitles them to seek, receive, and impart information relating to HIV testing and treatment. They have the right to bodily integrity and to physical privacy, which entitles them to withhold consent to medical treatment and testing. They also have the right to confidentiality of personal information, which entitles them to control the collection, use and disclosure of information relating to their HIV status.<sup>113</sup> Jurgens further notes:

*The right to be free of discrimination and the right to security of the person, also require that in both HIV testing policy and practice, governments take into account the outcomes of HIV testing for people—including stigma, discrimination, violence and other abuse—and do all that they can to prevent human rights violations associated with this health service.*<sup>114</sup>

<sup>109</sup> Open Society Foundations, *10 Reasons Why Human Rights Should Occupy the Centre of the Global AIDS Struggle* (2009). [www.hivhumanrightsnow.org](http://www.hivhumanrightsnow.org).

<sup>110</sup> Jurgens et al., “People who use drugs, HIV, and human rights,” *Lancet* 376 (2010): 475-485.

<sup>111</sup> UNAIDS and UN Office of the High Commissioner for Human, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

<sup>112</sup> UNAIDS and WHO, “UNAIDS/WHO policy statement on HIV testing” (2004). [www.who.int/hiv/pub/vct/statement/en/](http://www.who.int/hiv/pub/vct/statement/en/).

<sup>113</sup> UNAIDS and UN Office of the High Commissioner for Human, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

<sup>114</sup> Jurgens R, *Increasing Access to HIV Testing and Counseling While Respecting Human Rights* (Open Society Institute, 2007). [www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background](http://www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background).

Traditionally, there have been three main approaches to HIV testing in clinical settings. Opt-in approaches require patients to affirmatively agree to HIV testing after receiving pretest information. This client-initiated model has been shown to reduce HIV infection and transmission<sup>115</sup> while increasing uptake of testing.<sup>116</sup> Opt-out approaches, by contrast, require patients to specifically decline HIV testing after receiving pretest information. This provider-initiated model can result in increased testing,<sup>117</sup> but voluntariness may be compromised by poorly designed protocols, inadequate information about consent, and power imbalances between patients and providers.<sup>118</sup> The third approach, involuntary or mandatory testing,<sup>119</sup> involves no patient consent and is often required for populations such as prisoners, military recruits, migrants, and pregnant women. Where HIV testing is required as a precondition for marriage, this also implicates the right to marry and found a family.<sup>120</sup> UNAIDS and WHO do not support the mandatory HIV testing of individuals on public health grounds, and require “specific judicial authorization” to perform a mandatory HIV test.”<sup>121</sup>

In recent years, an international consensus in favor of expanded HIV testing has led to a reevaluation of HIV testing principles. Many in the public health community now advocate for the relaxing or elimination of counseling and informed consent requirements—such as HIV testing outside medical settings, mass HIV screening programs<sup>122</sup> and mandatory disclosure of HIV status to sexual partners.<sup>123</sup> These ideas are premised on the “right and responsibility” to know one’s HIV serostatus. They are also premised on the 1984 Siracusa Principles on the Limitation and Derogation of Principles, which permit limitations on individual rights “if [public health policies] are sanctioned by law, serve a legitimate public health goal, are necessary to achieve that goal, are no more intrusive or restrictive than necessary, and are non-discriminatory in application.”<sup>124</sup>

115 Amon J, “Preventing the Further Spread of HIV/AIDS: The Essential Role of Human Rights,” in Sudarshan N, ed., *HIV/AIDS, Health Care and Human Rights Approaches* (Amicus Books, Jan. 2009).

116 Ibid.

117 WHO, *Guidance on Provider-Initiated HIV Testing and Counselling in Health Facilities* (2007). [www.who.int/hiv/pub/guidelines/9789241595568\\_en.pdf](http://www.who.int/hiv/pub/guidelines/9789241595568_en.pdf)

118 Amon J, “Preventing the Further Spread of HIV/AIDS: The Essential Role of Human Rights,” in Sudarshan N, ed., *HIV/AIDS, Health Care and Human Rights Approaches* (Amicus Books, Jan. 2009). See also Jurgens R, *Increasing Access to HIV Testing and Counseling While Respecting Human Rights* (Open Society Institute, 2007). [www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background](http://www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background).

119 Involuntary measures are those undertaken against the individual’s will. Mandatory or compulsory measures are also undertaken against the individual’s will and may also be required by law.

120 Open Society Foundations, *Mandatory Pre-Marital HIV Testing: An Overview* (2010). <http://www.soros.org/sites/default/files/mandatory-premarital-hiv-testing-20100513.pdf>.

121 Amon J, “Preventing the Further Spread of HIV/AIDS: The Essential Role of Human Rights,” in Sudarshan N, ed., *HIV/AIDS, Health Care and Human Rights Approaches* (Amicus Books, Jan. 2009).

122 UNAIDS and UN Office of the High Commissioner for Human, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf). Also see Jurgens R, *Increasing Access to HIV Testing and Counseling While Respecting Human Rights* (Open Society Foundations, 2007). [www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background](http://www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background).

123 Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

124 Amon J, “Preventing the Further Spread of HIV/AIDS: The Essential Role of Human Rights,” in Sudarshan N, ed., *HIV/AIDS, Health Care and Human Rights Approaches* (Amicus Books, Jan. 2009).



Nevertheless, there is little evidence to suggest that relaxed consent standards meet these rigorous standards, let alone provide adequate safeguards against human rights violations. For example, women are disproportionately affected by coercive and involuntary approaches to HIV testing. According to Amon, studies in sub-Saharan Africa have found between 3.5 percent and 14.6 percent of women report abuse following the disclosure of test results.<sup>125</sup> Jurgens further notes that women may be exposed to higher risk of “criminalization in instances of not disclosing to a sexual partner and not using precautions—when it is precisely because women too often lack autonomy in their sexual relations as a result of violence, cultural norms, and/or economic subordination that they may be unable to disclose or to negotiate safer sex.”<sup>126</sup>

Expanding access to HIV testing must be accompanied by renewed commitment to voluntariness, confidentiality and informed consent, as well as measures to increase access to HIV treatment and to reduce vulnerability to the disease. As Amon notes:

*HIV testing in particular—as the entry point for access to anti-retroviral drugs and important services—must be accessible to all. But efforts to expand HIV testing, and to put in place “routine” testing, must not become coercive, must recognize the rights of the individuals being tested, and must provide linkages to both prevention and care.*<sup>127</sup>

## **Criminalizing HIV transmission and exposure inhibits advances in HIV prevention and treatment.**

Criminalization of HIV transmission inhibits advances in HIV prevention and treatment, deters people from being tested or disclosing their status and can negatively impact the underlying social determinants of health. The Global Commission on HIV and the Law found that “[i]n more than 60 countries, it is a crime to expose another person to or transmit HIV” and that “[m]ore than 600 HIV-positive people across 24 countries, including the United States, have been convicted of such crimes.”<sup>128</sup> The UN Special Rapporteur on the right to health notes that criminalization has no impact on changing behavior or limiting the spread of HIV. Furthermore, it undermines public health efforts and has a disproportionate impact on vulnerable communities.<sup>129</sup> Criminalization also forces individuals to disclose their HIV status, which is a violation of their rights and potentially dangerous to their person. Many individuals, especially women, cannot disclose their status without facing stigma, isolation, or violence.

<sup>125</sup> Ibid.

<sup>126</sup> Ibid.

<sup>127</sup> Jurgens R, *Increasing Access to HIV Testing and Counseling While Respecting Human Rights* (Open Society Institute, 2007). [www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background](http://www.opensocietyfoundations.org/publications/increasing-access-hiv-testing-and-counseling-while-respecting-human-rights-background).

<sup>128</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>129</sup> UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/14/20 (Apr. 27, 2010).

## Migration policies often discriminate on the basis of HIV status and increase vulnerability to HIV.

There are approximately 214 million international migrants and 740 million internal migrants worldwide.<sup>130</sup> Migrants are disproportionately vulnerable to HIV. According to the Global Commission on HIV and the Law:

*Migration policies—restrictions on entry, stay and residence in a country—split families and isolate people from their peers, friends and known ways. These conditions disempower people, exposing them to exploitation, changing their sexual behaviours and increasing the likelihood of unsafe practices. As a result, migrants face a risk of HIV infection that is as much as 3 times higher than that faced by people with secure homes.*

Immigration laws and policies often discriminate on the basis of HIV status. Under international law, it is not permitted to deny an asylum-seeker entry on the basis of their HIV status,<sup>131</sup> nor is it possible to detain or restrict the movement of a person on the basis of their HIV status.<sup>132</sup> Despite this, some countries still impose mandatory HIV testing for asylum and immigration applications, deny entry based upon HIV status,<sup>133</sup> and detain people with HIV indefinitely pending asylum or removal. Noncitizens are also excluded from national health care systems, leaving them without access to medical care and HIV treatment.<sup>134</sup> This constitutes a violation of their human rights while also impeding efforts to prevent and address HIV.

## Why a human rights response to HIV?

Protection of human rights, both of those vulnerable to infection and those already infected, is not only important for individuals, but also produces positive public health results. National and local responses to HIV will not work without the full engagement and participation of those affected by HIV, particularly people living with HIV. The human rights of women, young people, and children must be protected if they are to avoid infection and withstand the impact of HIV. The human rights of marginalized groups, including people who use drugs, sex workers, prisoners, and gay and bisexual men, must also be respected for the response to HIV to be effective.

When human rights principles guide implementation of local and national responses to HIV, the results are tailored to the needs and realities of those affected. Such principles include non-discrimination, participation, inclusion, transparency, and accountability. Where states provide comprehensive HIV prevention, care, and impact mitigation programs to all those in need—supporting vulnerable populations and allowing the full participation of all those affected in the design and implementation of HIV programs—they are fulfilling their HIV-related human rights obligations and mounting an effective response to HIV.

When human rights inform the content of national responses to HIV, vulnerability to HIV infection diminishes and people living with HIV can live with dignity. In contrast, where human rights are not respected, protected, and promoted, the risk of HIV infection is increased, people living with and affected by HIV suffer from discrimination, and an effective response to the epidemic is often impeded.

<sup>130</sup> Institute of Medicine (IOM), *World Migration Report 2011* (2011): 49. [http://publications.iom.int/bookstore/free/WMR2011\\_English.pdf](http://publications.iom.int/bookstore/free/WMR2011_English.pdf).

<sup>131</sup> UN Office of the High Commissioner of Human Rights, *10 Key Points on HIV/AIDS and the Protection of Refugees, IDPs and Other Persons of Concern*. [www.ohchr.org/Documents/Issues/HIV/SummaryHIV.pdf](http://www.ohchr.org/Documents/Issues/HIV/SummaryHIV.pdf); UNAIDS, *Denying Entry, Stay and Residence Due to HIV Status: Ten Things You Need to Know*. [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/basedocument/2009/jc1738\\_entry\\_denied\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/basedocument/2009/jc1738_entry_denied_en.pdf).

<sup>132</sup> Ibid.

<sup>133</sup> International AIDS Society (IAS), HIV-specific entry and residence restrictions, IAS Policy Paper (2009). [www.iasociety.org/Web/WebContent/File/ias\\_policy%20paper.pdf](http://www.iasociety.org/Web/WebContent/File/ias_policy%20paper.pdf). List of countries with restrictions are provided in the Annex.

<sup>134</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012): 60-61. <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

## What are rights-based interventions and practices in the area of HIV?

The protection of human rights is essential to mounting an effective public health response to HIV and safeguarding human dignity. At the same time, an effective response to HIV requires the realization of all human rights in accordance with international human rights standards. As the IPU states, “A rights-based, effective response to the HIV epidemic involves establishing appropriate government institutional responsibilities, implementing law reform and support services, and promoting a supportive environment for groups vulnerable to HIV and for those living with HIV.”<sup>135</sup> Programmatic reforms to address human rights violations must be incorporated in national HIV programs, including measures to combat discrimination and violence against people infected and affected by HIV. Equally, there must be new laws and policies to address the human rights violations that place vulnerable and marginalized populations at risk of HIV.<sup>136</sup>

Many of the following interventions and practices are modeled on the OHCHR/UNAIDS *International Guidelines on HIV/AIDS and Human Rights*. These 12 guidelines—issued in 1998 at the request of what is now the UN Human Rights Council and reissued in 2006<sup>137</sup>—are an essential resource for governments, policymakers, activists, institutions, and other stakeholders. Since then, UNAIDS has developed a supplemental framework called the 2011 *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses*. Together, the *International Guidelines* and *Key Programmes* represent several decades of best practice and should be included in all national responses to HIV. The following list provides an overview and is not intended to be comprehensive. For additional recommendations, please refer to both documents, as well the resources listed at the end of this chapter.

### National Frameworks for HIV Response

Each country’s HIV epidemic has distinctive drivers, vulnerabilities, aggravating factors, and affected populations.<sup>138</sup> To address these social and epidemiological complexities, states should establish a national HIV framework that mobilizes key actors and institutions and includes national HIV action plans, strategies, and activities. At the same time, they should ensure the integration of HIV and human rights into all public sectors, including health, education, law and justice, social security and housing, employment and public service and immigration, among others. States should also establish and strengthen national mechanisms for addressing HIV-related legal, ethical, and human rights issues. An effective, well-integrated, and coordinated national framework for HIV response can help harmonize national laws and policy priorities, facilitate stakeholder engagement and ensure the protection of human rights.<sup>139</sup>

<sup>135</sup> Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

<sup>136</sup> Amon J, “Preventing the Further Spread of HIV/AIDS: The Essential Role of Human Rights,” in Sudarshan N, ed., *HIV/AIDS, Health Care and Human Rights Approaches* (Amicus Books, Jan. 2009).

<sup>137</sup> Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

<sup>138</sup> Ibid.

<sup>139</sup> UN Office of the High Commissioner for Human Rights and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines_en.pdf).

## Community Partnership and Consultation

National responses to the epidemic should include consultation and partnership with community representatives in all phases of HIV policy, programs and evaluation. Community representation should comprise people living with HIV, community-based organizations, administrative services organizations, human rights NGOs, and representatives of vulnerable groups, since these individuals and organizations have highly relevant knowledge and experience of HIV and human rights. States should establish formal and regular mechanisms to facilitate ongoing dialogue with community partners. States also ensure they have political and financial support for activities relating to HIV, law, ethics and human rights.<sup>140</sup>

## “Therapeutic Citizenship”, Self-Help, and Empowerment

The experience in some African countries has demonstrated the strengths of “therapeutic citizenship” in promoting access to treatment and improving adherence, particularly in resource-constrained settings. According to Nguyen et al., therapeutic citizenship refers to “the way in which people living with HIV appropriate ART as a set of rights and responsibilities” that is less focused on negotiating biosocial vulnerability than social and institutional relationships.<sup>141</sup> Robins describes the efforts of one organization, the Treatment Action Campaign in South Africa:

*Whereas public health practitioners report that most of their HIV/AIDS patients wish to retain anonymity and invisibility at all costs, TAC successfully advocates the transformation of the stigma of HIV/AIDS into a “badge of pride.” It is through these activist mediations that it becomes possible for the social reintegration and revitalization of large numbers of isolated and stigmatized HIV/AIDS sufferers into a social movement and a caring community—a HIV/AIDS activist culture.<sup>142</sup>*

These collectivist responses to HIV and treatment have created an empowering experience and resulted in a network of informed activists who are better able to navigate the health system and advise others on how to best negotiate the health care system.<sup>143</sup>

<sup>140</sup> Ibid.

<sup>141</sup> Robins, S. 2006. “From ‘Rights’ to ‘Ritual’”: AIDS Activism in South Africa.” *American Anthropologist* 108(2):312-323. <http://onlinelibrary.wiley.com.ezp-prod1.hul.harvard.edu/doi/10.1525/aa.2006.108.2.312/pdf>; Nguyen VK, “Chapter 17: Trial Communities: HIV and Therapeutic Citizenship in West Africa,” *Evidence, Ethos and Experience: The Anthropology and History of Medical Research in Africa*, Geissler WP and Molyneux C, eds., (Berghahn Books, 2011).

<sup>142</sup> Robins, S. 2006. “From ‘Rights’ to ‘Ritual’”: AIDS Activism in South Africa.” *American Anthropologist* 108(2):312-323. <http://onlinelibrary.wiley.com.ezp-prod1.hul.harvard.edu/doi/10.1525/aa.2006.108.2.312/pdf>.

<sup>143</sup> Robins, S. 2006. “From ‘Rights’ to ‘Ritual’”: AIDS Activism in South Africa.” *American Anthropologist* 108(2):312-323. <http://onlinelibrary.wiley.com.ezp-prod1.hul.harvard.edu/doi/10.1525/aa.2006.108.2.312/pdf>; Nguyen VK, “Chapter 17: Trial Communities: HIV and Therapeutic Citizenship in West Africa,” *Evidence, Ethos and Experience: The Anthropology and History of Medical Research in Africa*, Geissler WP and Molyneux C, eds., (Berghahn Books, 2011).

## Public Health Legislation

States should review and reform public health legislation and practices so that they support access to HIV and health services.<sup>144</sup> Specifically, legislation should ensure provision of comprehensive HIV prevention and treatment services—such as information and education, voluntary testing and counseling, sexual and reproductive health services, condoms, harm reduction services, drug treatment, antiretroviral therapy, treatment for HIV/AIDS-related illnesses and palliative care.<sup>145</sup> Legislation should also ensure that HIV testing is only performed with an individual’s specific, informed consent, provide for pre-test and post-test counseling and protect against unauthorized collection, use or disclosure of information relating to HIV status. No one should be subjected to coercive measures such as isolation, detention or quarantine based on their HIV status.<sup>146</sup>

## Criminal Laws and Correctional Systems

Punitive laws, correctional systems, and denial of access to justice for people infected and affected by HIV are fueling the epidemic.<sup>147</sup> States should review and reform criminal legislation, correctional systems and law enforcement practices to ensure they are “consistent with international human rights obligations and are not misused in the context of HIV or targeted at vulnerable groups.”<sup>148</sup> The following measures are among those recommended:

- **Decriminalize the transmission of HIV.** At most, “criminalization should be considered permissible only in cases involving intentional, malicious transmission.”<sup>149</sup>
- **Decriminalize homosexuality and decriminalize same-sex relations.** This is an important step to reducing the stigma, discrimination and inequality increases the vulnerability of men who have sex with men.
- **Decriminalize sex work and provide support to sex workers.** Criminalization exposes sex workers to violence, exploitation and victimization, including from police. Creating safer working environments and ensuring access to health services, advocacy and other forms of support enable sex workers to seek services and protection without fear of criminal penalties.<sup>150</sup>
- **Reform approaches to drug use and advocate for non-discriminatory treatment of people who inject drugs.** Harsh and punitive drug laws exacerbate harms associated with drug use. States should offer harm reduction programs and voluntary, evidence-based treatment.<sup>151</sup>

<sup>144</sup> UNAIDS, *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses* (2012). [http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_May2012.pdf).

<sup>145</sup> UN Office of the High Commissioner for Human Rights and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). <http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines>.

<sup>146</sup> Ibid.

<sup>147</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>148</sup> UN Office of the High Commissioner for Human Rights and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf).

<sup>149</sup> UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/14/20 (Apr. 27, 2010). <http://www2.ohchr.org/english/bodies/hrcouncil/14session/reports.htm>.

<sup>150</sup> UNAIDS, *UNAIDS Guidance Note on HIV and Sex Work* (2009). [www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2009/JC2306\\_UNAIDS-guidance-note-HIV-sex-work\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2009/JC2306_UNAIDS-guidance-note-HIV-sex-work_en.pdf).

<sup>151</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

- **Review laws, policies, and practices that prevent prisoners from accessing HIV-related services.** Prisoners are entitled to the same rights as other individuals, “with the exception of restrictions on liberty directly related to their imprisonment,” and should have access to health information, treatment, care, and support.<sup>152</sup>

A necessary complement to legislative and criminal justice reform is the sensitization of lawmakers and law enforcement agencies and personnel to the role of law, ethics and human rights in the HIV response. Such programs can “help ensure that individuals living with and vulnerable to HIV can access HIV services and lead full and dignified lives, free from discrimination, violence, extortion, harassment, and arbitrary arrest and detention.”<sup>153</sup>

## Anti-Discrimination and Protective Laws

Enabling legal, social and policy environments are necessary to eliminate HIV-related stigma, discrimination, and violence, to provide legal protections for people affected by HIV, and to promote and protect the human rights in the context of HIV.<sup>154</sup> States should therefore enact or strengthen anti-discrimination and other protective laws that protect people living with HIV or members of vulnerable populations from discrimination in both the public and private sectors, ensure privacy and confidentiality and provide access to justice for HIV-related right violations.<sup>155</sup> Specific recommendations include, but are not limited to:

- Explicitly prohibit discrimination against people based on actual or perceived HIV status, covering “health care, social security, welfare benefits, employment, education, sport, accommodation, clubs, trades unions, qualifying bodies, access to transport and other services”;<sup>156</sup>
- Abolish mandatory HIV-related registration, testing and forced treatment;
- Work with guardians of traditional and customary laws for consistency with anti-discrimination principles and provide legal remedies for misuse;<sup>157</sup>
- Enact general privacy and confidentiality laws, including the use of HIV-related information;<sup>158</sup> and
- Promote and protect the rights of vulnerable and at-risk populations, including women, children, young persons, men who have sex with men, sex workers, prisoners, and other people in detention settings and people living with HIV.<sup>159</sup>

<sup>152</sup> UNAIDS and UN Office of the High Commissioner for Human, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

<sup>153</sup> UNAIDS, *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses* (2012). [http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_May2012.pdf).

<sup>154</sup> See 2011 Political Declaration

<sup>155</sup> UN Office of the High Commissioner for Human and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines_en.pdf).

<sup>156</sup> Ibid.

<sup>157</sup> UN Office of the High Commissioner for Human and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines_en.pdf). See also Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>158</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>159</sup> UNAIDS and UN Office of the High Commissioner for Human, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).



The IPU's *Handbook for Legislators on HIV/AIDS, Law and Human Rights* provides a checklist of key components of anti-discrimination legislation, privacy legislation and employment legislation to help stakeholders develop longer-term, strategic plans and programs to address HIV-related stigma and discrimination.<sup>160</sup>

## Universal Access to HIV Prevention, Treatment, Care, and Support

Vast inequities in access to HIV prevention, treatment, care, and support violate a number of human rights—including the right to health, the right to non-discrimination and equality before the law, the right to an adequate standard of living and social security, the right to participation in political and cultural life, and the right to enjoy the benefits of scientific progress.<sup>161</sup> States should therefore enact legislation, policies and other measures to ensure universal and equal access to appropriate, affordable and quality HIV-related goods, services and information, “including antiretroviral and other safe and effective medicines, diagnostics and related technologies for preventive, curative and palliative care of HIV and related opportunistic infections and conditions.”<sup>162</sup>

States should make sufficient resources available to meet the commitments outlined in their national HIV strategies, strengthen their health systems and address health-worker shortages. States should also strive to make HIV medicines more affordable for all. A barrier to access is a global intellectual property (IP) protection regime that hinders the production and distribution of low-cost medicines. The IP regulations enforced by the World Trade Organization's TRIPS (“The Agreement on Trade Related Aspects of Intellectual Property Rights”) enable pharmaceutical companies to maintain monopolies on drug patents, resulting in higher costs and “catastrophic” outcomes for resource-poor countries unable to afford HIV medicines.<sup>163</sup> The IPU recommends the following measures to address the situation:

*A number of mechanisms are available to help make HIV medicines more affordable. These include generic competition, local production, differential pricing by research-based and generic pharmaceutical companies, voluntary licensing by innovator to generic companies, high-volume and bulk-purchasing arrangements, elimination of tariffs and taxes on essential medicines, and the use of flexibilities in the international trade and intellectual property rules (through the TRIPS Agreement and other WTO mechanisms) to achieve wider access to affordable generic medicines.*

The Global Commission on HIV and the Law thus urges all countries to suspend TRIPS as it relates to essential medicines and adopt a “moratorium on the inclusion of any intellectual property provisions in any international treaty that would limit the ability of countries to retain policy options to reduce the cost of HIV-related treatment.”<sup>164</sup>

<sup>160</sup> Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

<sup>161</sup> UNAIDS and UN Office of the High Commissioner for Human, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv\\_en.pdf](http://data.unaids.org/pub/Report/2007/jc1367-handbookhiv_en.pdf).

<sup>162</sup> UN Office of the High Commissioner for Human and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf).

<sup>163</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>164</sup> Ibid.

Finally, States should also address barriers to equal access by vulnerable populations, such as poverty, migration, rural location, and discrimination.<sup>165</sup> Social protection programs can promote the uptake of HIV services while alleviating the social and economic impacts of HIV.<sup>166</sup> According to UNICEF, “HIV sensitive social protection can be grouped into three broad categories of interventions: financial protection through predictable transfers of cash or food for those HIV-affected and most vulnerable; access to affordable quality services including treatment, health, and education services; and policies, legislation and regulation to meet the needs and uphold the rights of the most vulnerable and excluded.”<sup>167</sup>

## Legal Support Services

According to OHCHR, “States should implement and support legal support services that will educate people affected by HIV about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of Ministries of Justice, ombudspersons, health complaint units and human rights commissions.”<sup>168</sup> The provision of HIV-related legal services can facilitate access to justice and redress in cases of HIV-related discrimination or other legal matters, including but not limited to “estate planning; breaches of privacy and confidentiality; illegal action by the police; discrimination in employment, education, housing or social services; and denial of property and inheritance rights.” At the same time, legal literacy programs and campaigns (“Know Your Rights”) teach people about human rights and laws relevant to HIV, enabling them to organize around these rights advocate for their needs.<sup>169</sup>

## Reducing Vulnerability Among Key Groups

### Women and Girls

“Gender inequality, gender-based violence, and the low status of women remain three of the principal drivers of HIV.” Addressing the political, social, economic, and sexual subordination of women and girls is therefore critical to reducing their vulnerability to HIV.<sup>170</sup> States should enact or strengthen laws to protect women’s equal rights in a broad range of areas, including:

- **Education.** Education is instrumental in providing information on HIV itself, but also in empowering women and providing a means for their economic and social independence.
- **Inheritance and Property Ownership.** Unequal inheritance and property laws and customs deprive women of the financial and social resources to prevent infection and mitigate the consequences of HIV.<sup>171</sup>
- **Employment and Compensation.** Equal rights to employment and fair compensation provide the opportunity to offset the costs of care associated with HIV or the loss of an income-earning partner or family member.

<sup>165</sup> UN Office of the High Commissioner for Human and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf).

<sup>166</sup> Nolan A, *Social Protection in the Context of HIV and AIDS* (OECD, 2009), [www.oecd.org/development/povertyreduction/43280854.pdf](http://www.oecd.org/development/povertyreduction/43280854.pdf).

<sup>167</sup> UNICEF, *Enhancing Social Protection for HIV Prevention, Treatment, Care & Support – The State of Evidence* (2010). [www.unicef.org/aids/files/Social\\_Protection\\_Brief\\_LowresOct2010.pdf](http://www.unicef.org/aids/files/Social_Protection_Brief_LowresOct2010.pdf).

<sup>168</sup> UN Office of the High Commissioner for Human and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf).

<sup>169</sup> UNAIDS, *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses* (2012). [http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_May2012.pdf).

<sup>170</sup> Ibid.

<sup>171</sup> Strickland R, *To Have and To Hold: Women’s Property and Inheritance Rights in the Context of HIV/AIDS in Sub-Saharan Africa* (International Center for Research on Women, June 2004). [www.icrw.org/files/publications/To-Have-and-To-Hold-Womens-Property-and-Inheritance-Rights-in-the-Context-of-HIV-AIDS-in-Sub-Saharan-Africa.pdf](http://www.icrw.org/files/publications/To-Have-and-To-Hold-Womens-Property-and-Inheritance-Rights-in-the-Context-of-HIV-AIDS-in-Sub-Saharan-Africa.pdf).



- **Gender-Based Violence, Domestic Violence, and Spousal Rape.** Measures to eliminate violence against women include: enactment of formal laws, like those that criminalize marital rape; policy and program changes; training programs for police and health care providers; increased health and psychological services; and legal recourse for rights violations.
- **Equitable Budgetary Allotment.** Only 46% of countries allocate resources for the specific needs of women and girls into HIV programs.<sup>172</sup> HIV programs must incorporate women and their needs and countries must demonstrate their commitment through budgetary allotment.
- **Sexual and Reproductive Health Rights.** Providing information and access to reproductive services enables women to protect themselves against HIV and mitigate its consequences. Formal educational efforts, as well as health providers and mediators can provide women with information on HIV.

## Children

Less than a quarter of children in need of ART receive treatment,<sup>173</sup> and children affected by the loss of a caregiver from HIV-related causes are at grave risk of human rights violations. States should therefore reduce the vulnerability of children and to protect their rights through the following measures: laws protecting orphans and other vulnerable children from abuse, violence, exploitation, and discrimination; full implementation of the Convention on the Rights of the Child and its Optional Protocols into national legislation; laws, policies, and practices to prevent mother-to-child transmission and to increase access to affordable HIV treatment for children; and policies and programs to enable children to stay in school.<sup>174</sup> Additional measures aimed at the empowerment of children include ensuring access to health information and education; education about the rights of persons, including children, living with HIV; and access to confidential sexual and reproductive health services.<sup>175</sup>

## Young People

Young people aged 15 to 24 represent half of all new HIV infections, and young women are disproportionately vulnerable. States should address the specific needs of this population by ensuring that they have full access to HIV prevention, treatment, care and support, including comprehensive sex and health information and education. Programs should also address HIV-related ignorance, fear, and prejudice by empowering young people to discuss and address the social and cultural issues related to the epidemic, including gender-discrimination, violence, exploitation, and rape. Finally, the IPU recommends ensuring that young people have life skills education “to develop healthy attitudes and the negotiating capacity to make informed, healthy choices about sex, drugs, relationships and other issues.”<sup>176</sup>

<sup>172</sup> UNAIDS, *Report on the global AIDS epidemic 2010* (2010) [www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm).

<sup>173</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>174</sup> Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

<sup>175</sup> UN Office of the High Commissioner for Human and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf).

<sup>176</sup> Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

### Men Who Have Sex With Men

Men who have sex with men are frequently marginalized by society, and many HIV programs and policies do not address their specific needs. As a result, they experience high rates of infection. Laws and policies should address the stigma and discrimination experienced by men who have sex with men and increase access to HIV prevention and treatment services. Countries should also enact anti-discrimination laws, implement privacy laws for same-sex relations, create measures to prevent violence and permit gay, lesbian and bisexual groups to organize.<sup>177</sup>

### Sex Workers

Sex workers are highly vulnerable to infection and often lack access to HIV services “due to exploitation within the industry, as well as widespread police abuse.”<sup>178</sup> OHCHR/UNAIDS recommend that adult sex work that involves no victimization should be decriminalized, and then legally regulated with respect to occupational health and safety conditions. This can protect both sex workers and their clients, including support for safe sex during sex work.<sup>179</sup> Additionally, sex workers should be provided full and equal access to HIV prevention, treatment, care, and support services, tailored to their needs and consistent with their fundamental human rights.

### People Who Inject Drugs

In many countries, people who use illicit drugs account for the majority of people living with HIV but they are the least likely to receive ART. To reduce the vulnerability of this population and to eliminate one of the key drivers of the HIV epidemic, states should put in place rights-based and evidence-based programs that are effective in reducing the risk behaviours and vulnerability to HIV of people who use drugs, including needle and syringe programs, voluntary drug treatment programs, sensitization of health care providers and law enforcement personnel, equal access to ART and care services, peer education and outreach, and access to legal assistance and legal remedies for rights violations.<sup>180</sup>

### Prisoners

Many prisoners have little or no access to voluntary HIV prevention information and tools or to HIV testing or treatment. States should scale up funding as well as access to health services for prisoners, including HIV services. Specific measures to reduce vulnerability include provision of condoms and needles and syringes, as well as criminal justice reform to reduce the number of people in prison—e.g., decriminalizing the status of drug users and limiting pretrial detention.<sup>181</sup>

<sup>177</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>178</sup> Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

<sup>179</sup> UN Office of the High Commissioner for Human and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf).

<sup>180</sup> Inter-Parliamentary Union, *Handbook for Parliamentarians on HIV/AIDS, Law and Human Rights* (2007). [http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

<sup>181</sup> Ibid.

## Education, Training, and Media

While many countries outlaw discrimination based on HIV, these laws are routinely ignored, unenforced or flouted. According to the Global Commission on HIV and the Law:

*To make law real on the ground, the state must educate health care workers, legal professionals, employers and trade unionists, and school faculties about their legal responsibilities to guarantee inclusion and equality.*<sup>182</sup>

The goal of education and training is to inform people living with HIV of their rights, as well to challenge beliefs based on ignorance, fear, prejudice, and moral judgment. States should therefore “promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV to understanding and acceptance.”<sup>183</sup>

## Public and Private Sector Standards and Mechanism

OHCHR/UNAIDS recommend that “[s]tates should ensure that Government and the private sector develop codes of conduct regarding HIV issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.”<sup>184</sup> This includes training health care providers and other professionals in health care settings on human rights and medical ethics related to HIV. As UNAIDS notes:

*Human rights and ethics training for health care providers focus on two objectives. The first is to ensure that health care providers know about their own human rights to health (HIV prevention and treatment, universal precautions, compensation for work-related infection) and to non-discrimination in the context of HIV. The second is to reduce stigmatizing attitudes in health care settings and to provide health care providers with the skills and tools necessary to ensure patients’ rights to informed consent, confidentiality, treatment and non-discrimination.*<sup>185</sup>

## Monitoring and Enforcement of Human Rights

OHCHR/UNAIDS recommend that “[s]tates should ensure monitoring and enforcement mechanisms to guarantee HIV-related human rights, including those of people living with HIV, their families and communities.”<sup>186</sup>

## International Cooperation

OHCHR/UNAIDS recommend that “[s]tates should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues, and should ensure effective mechanisms to protect human rights in the context of HIV at the international level.”<sup>187</sup>

<sup>182</sup> Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012). <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>.

<sup>183</sup> UN Office for the High Commissioner for Human Rights and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines_en.pdf).

<sup>184</sup> Ibid.

<sup>185</sup> UNAIDS, *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses* (2012). [http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_May2012.pdf).

<sup>186</sup> UN Office for the High Commissioner for Human Rights and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006). [http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines_en.pdf).

<sup>187</sup> Ibid.

## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO HIV?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to HIV. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<p><b>UN treaty body interpretation</b></p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
<b>Human rights standards</b>	<p><b>Case law</b></p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and HIV.

## Abbreviations

In the tables, we use the following abbreviations to refer to the eleven treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )

Also cited are the former Commission on Human Rights (CHR) and various UN Special Rapporteurs (SR) and Working Groups (WG).

**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Life	Art. 3	Art. 6(1)				Art. 6(1)
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)
Liberty and Security of Person	Art. 3	Art. 9(1)			Art. 5(b)	
Enjoy and Seek Asylum	Art. 14					
Privacy	Art. 12	Art. 17				Art. 16
Expression and Information	Art. 19	Art. 19(2)			Art. 5(d) (viii)	Art. 12, Art. 13, Art. 17
Assembly and Association	Art. 20	Art. 21, Art. 22			Art. 5(d) (ix)	Art. 15
Marry and Found a Family	Art. 16	Art. 23(2)		Art. 16(1)	Art. 5(d) (iv)	
Non-discrimination and Equality	Art. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24
Women and Children	Art 16, Art. 25(2)	Art. 3, Art. 23, Art. 24	Art. 3, Art. 10, Art. 12(2) (a)	All		All

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

**Table B: Regional Human Rights Instruments & Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Life	Art. 3	Art. 6(1)				Art. 6(1)
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)
Liberty and Security of Person	Art. 3	Art. 9(1)			Art. 5(b)	
Enjoy and Seek Asylum	Art. 14					
Privacy	Art. 12	Art. 17				Art. 16
Expression and Information	Art. 19	Art. 19(2)			Art. 5(d) (viii)	Art. 12, Art. 13, Art. 17
Assembly and Association	Art. 20	Art. 21, Art. 22			Art. 5(d) (ix)	Art. 15
Marry and Found a Family	Art. 16	Art. 23(2)		Art. 16(1)	Art. 5(d) (iv)	
Non-discrimination and Equality	Art. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24
Women and Children	Art 16, Art. 25(2)	Art. 3, Art. 23, Art. 24	Art. 3, Art. 10, Art. 12(2) (a)	All		All

**Table I: HIV, AIDS and the right to life**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Police fail to investigate the murder of a person living with HIV.</li> <li>• Government places unjustified legal restrictions on access to life-saving HIV-prevention or treatment measures.</li> <li>• Government imposes a death sentence for intentional transmission of HIV.</li> <li>• Woman is denied access to post-exposure prophylaxis to prevent HIV following rape.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 6(1)</b> Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.</p>	<p><b>HRC General Comment 6:</b> Explaining that Art. 6 of the ICCPR creates positive obligations on States to protect life, and that “the Committee considers that it would be desirable for States parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics.” ¶5 (1982).</p> <p><b>HRC:</b> Interpreting the right to life, the HRC has recommended that <b>Namibia</b> “pursue efforts to protect its population from HIV/AIDS” and “adopt comprehensive measures encouraging and facilitating greater numbers of persons suffering from HIV and AIDS to obtain adequate antiretroviral treatment and facilitate such treatment.” CCPR/CO/81/NAM (July 30, 2004).</p> <p><b>HRC:</b> Recommending “equal access to treatment” in <b>Kenya</b>. CCPR/CO/83/KEN (April 29, 2005).</p> <p><b>HRC:</b> Recommending that <b>Uganda</b> “allow greater number of persons suffering from HIV/AIDS to obtain adequate antiretroviral treatment.” CCPR/CO/80/UGA (May 4, 2004).</p>

Human Rights Standards	Case Law
<p><b>ECHR 2(1):</b> Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.</p>	<p><b>ECtHR:</b> The applicant argued that the decision to remove him from the U.K. where he receives antiretroviral drugs to control his case of HIV to St. Kitts where he would likely be unable to obtain antiretroviral drugs necessary to prevent his death from HIV/AIDS-related illness would violate Art. 2. The Court found that the complaint under Art. 2 is “indissociable” from the substance of the complaint under Art. 3 (freedom from inhuman or degrading treatment). <i>D.V. v. The United Kingdom</i>, 30240/96 (May 2, 1997).</p>



**Table 2: HIV, AIDS and freedom from torture and cruel, inhuman, and degrading treatment, including in prison**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Outreach workers conducting HIV prevention with MSM are detained and beaten by police.</li> <li>• An activist is detained and tortured for exposing State complicity in a HIV blood scandal.</li> <li>• Prisoners are denied HIV-related information, education, means of prevention (e.g., condoms, sterile injection equipment, and bleach) and HIV testing/treatment.</li> <li>• Authorities fail to take steps to prosecute or prevent prison rape.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 7:</b> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.</p>	<p><b>HRC:</b> expressing concern about the “high incidence of HIV/ AIDS and tuberculosis among detainees in facilities of the State party. . . along with absence of specialized care for pre-trial detainees” in <b>Ukraine</b>. The Committee recommended that Ukraine relieve prison overcrowding, provide hygienic facilities, assure access to health care and adequate food and reduce the prison population, including by using alternative sanctions. CCPR/C/UKR/CO (2006).</p>

Human Rights Standards	Case Law
<p><b>ECHR 3:</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.</p>	<p><b>ECtHR:</b> finding failure to provide a prisoner with timely and appropriate AIDS and TB treatment to constitute a violation of the right to freedom from torture and inhuman or degrading treatment. <i>Yakovenko v. Ukraine</i>, 15825/06 (October 25, 2007).</p> <p><b>ECtHR:</b> The applicant applied for and was refused asylum in the U.K. Her claim under Art. 3 was based on her medical condition (HIV/AIDS) and the lack of sufficient treatment in her home country. The Court found that the deterioration that she would suffer involved a certain degree of speculation and that it did not involve exceptional circumstances. Therefore, the Court found no violation of Art. 3. <i>N. v. The United Kingdom</i>, 26565/05 (May 27, 2008).</p>

**Other Interpretations**

**Standard Minimum Rules for the Treatment of Prisoners (1955)**

Principle 22(2): Sick prisoners who require specialist treatment shall be transferred to specialized institutions or to civil hospitals. Where hospital facilities are provided in an institution, their equipment, furnishings and pharmaceutical supplies shall be proper for the medical care and treatment of sick prisoners, and there shall be a staff of suitable trained officers.

Principle 24: The medical officer shall see and examine every prisoner as soon as possible after his admission and thereafter as necessary, with a view particularly to the discovery of physical or mental illness and the taking of all necessary measures; the segregation of prisoners suspected of infectious or contagious conditions; the noting of physical or mental defects which might hamper rehabilitation, and the determination of the physical capacity of every prisoner for work.

**Table 3: HIV, AIDS and the right to liberty and security of the person**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Government quarantines people living with HIV or detains them in special colonies.</li> <li>• Penal code imposes explicit prison term for intentional transmission of HIV.</li> <li>• Government requires HIV testing either for all individuals or as a condition of employment, immigration or military service.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 9:</b> Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.</p>	<p>None</p>
Human Rights Standards	Case Law
<p><b>ECHR 5(1):</b> Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save [for those cases enumerated in this article and only in accordance with the law].</p>	<p><b>ECtHR:</b> The Court held that the involuntary placement in the hospital of an HIV-positive gay man to prevent him from spreading HIV to others violated Art. 5. The Court found that the “compulsory isolation of the applicant was not a last resort in order to prevent him from spreading the HIV virus because less severe measures had not been considered and found to be insufficient to safeguard the public interest. Moreover, the Court considered that by extending over a period of almost seven years the order for the applicant’s compulsory isolation, with the result that he was placed involuntarily in a hospital for almost one and a half years in total, the authorities failed to strike a fair balance between the need to ensure that the HIV virus did not spread and the applicant’s right to liberty.” <i>Enhorn v. Sweden</i>, 56529/00 (January 25, 2005).</p>

**Other Interpretations**

**Working Group on Arbitrary Detention:** expressed concern at the arbitrary detention of “drug addicts” and “people suffering from AIDS.” Recommended that persons deprived of their liberty on health grounds “must have judicial means of challenging their detention.” (2003)

**Code of Conduct for Law Enforcement Officials** (1979)

**Basic Principles on the Use of Force and Firearms by Law Enforcement Officials** (1990)

**Table 4: HIV, AIDS and the right to seek and enjoy asylum**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• A State returns an asylum-seeker to a country where she or he faces persecution on the basis of HIV status or HIV activism.</li> <li>• A State excludes persons living with HIV from being granted asylum, or discriminates on the basis of HIV status in the context of travel regulations, entry requirements or immigration and asylum procedures.</li> <li>• Refugees and asylum seekers face discrimination in access to HIV prevention and treatment services.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 14(1):</b> All persons shall be equal before the courts and tribunals.</p>	<p><b>HRC:</b> Has confirmed that the right to equal protection of the law prohibits discrimination in law or in practice in any fields regulated and protected by public authorities. This would include travel regulations, entry requirements, and immigration and asylum procedures.</p>
Human Rights Standards	Case Law
<p><b>ECHR 14:</b> The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.</p>	<p><b>ECTHR:</b> Held that refusing a residence permit to a foreign national solely on the basis of their HIV-positive status amounted to unlawful discrimination. <i>Kiyutin v. Russia</i>, 2700/10 (March 10, 2011).</p>

**Other Interpretations**

**Special Rapporteur on Trafficking:** Recommending to **Lebanon** that “[p]otential victims of trafficking and exploitation, including women that have contracted HIV/AIDS or other sexually transmitted diseases, must not be immediately deported but given adequate legal, medical and social assistance, including access to interpretation in language they understand.”  
E/CN.4/2006/62/Add.3 (SR Trafficking, 2006)

**Geneva Convention Relating to the Status of Refugees (as amended by the 1967 Protocol Relating to Status of Refugees).** Defining “refugee” and providing rule of non-refoulement.

**Convention Against Torture 3(1):** No State Party shall expel, return (“refouler”) or extradite a person to another State where there are substantial grounds for believing that he would be in danger of being subjected to torture.

The **United Nations High Commissioner for Refugees** issued policy guidelines in 1988 stating that refugees and asylum seekers should not be targeted for special measures regarding HIV infection and that there is no justification for screening to exclude HIV-positive individuals from being granted asylum.

**Declaration of Territorial Asylum**, G.A. Res. 2312 (XXII) (December 14, 1967).

**Convention Governing the Specific Aspects of Refugee Problems in Africa**, adopted September 10, 1969 (entered into force June 20, 1974).

**Recommended Guidelines on Human Rights and Human Trafficking**

**Guideline 2(7):** Ensuring that procedures and processes are in place for receipt and consideration of asylum claims from both trafficked persons and smuggled asylum seekers ...

**Guideline 6(8):** Measures should be taken to ensure the provision of appropriate physical and psychological health care, housing and educational and employment services for returned trafficking victims.

**HIV-related restrictions on entry, stay, and residence**, UNAIDS Human Rights and Law Team, July 2012, available at: [www.unaids.org/en/media/unaids/contentassets/documents/factsheet/2012/20120724CountryList\\_TravelRestrictions\\_July2012.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/factsheet/2012/20120724CountryList_TravelRestrictions_July2012.pdf). Restrictions listed by country.

**Table 5: HIV, AIDS and the right to privacy**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A person is tested for HIV without his or her consent.</li> <li>• A hospital or health care worker fails to maintain confidentiality of a patient’s HIV status or medical records.</li> <li>• Government requires registration by name of all people living with HIV.</li> <li>• Government requires disclosure of HIV status on certain forms such as sick-leave certificates, job applications, and medical prescriptions.</li> <li>• Penal code criminalizes certain sexual acts between consenting adults, such as fornication, oral sex, anal sex, or adultery.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 17(1):</b> No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honor and reputation.</p> <p><b>ICCPR 17(2):</b> Everyone has the right to the protection of the law against such interference or attacks.</p>	<p><b>HRC [Jurisprudence]:</b> In finding that the right to privacy is violated by laws that criminalize homosexual acts between consenting adults, the Human Rights Committee noted that “...the criminalization of homosexual practices cannot be considered a reasonable means or proportionate measure to achieve the aim of preventing the spread of HIV and AIDS...[B]y driving underground many of the people at risk of infection...[it] would appear to run counter to the implementation of effective education programmes in respect of the HIV and AIDS prevention.” <i>Toonen v. Australia</i>, CCPR/C/50/D/488/1992 (March 31, 1994).</p>
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR:</b> Recommending to <b>Moldova</b> that “the state party ensure the confidentiality of a patient’s HIV status, including through reforming the law on HIV/AIDS, and reform of the data management system on HIV/AIDS. The committee also recommends that the state party take steps to eliminate the mandatory indication of disease codes on all medical sick leave forms.” E/C.12/MDA/CO/2 (CESCR, 2011)</p>
<p><b>CEDAW 12(1):</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services.</p>	<p><b>CEDAW Committee General Recommendation No. 24:</b> Explaining that “[t]he issue of HIV/AIDS and other sexually transmitted disease are central to the rights of women and adolescent girls to sexual health. . . . In particular, States parties should ensure the rights of female and male adolescents to sexual and reproductive health education by properly trained personnel in specially designated programmes that respect their rights to privacy and confidentiality.” Para. 18 (20th Session, 1999).</p> <p><b>CEDAW Committee General Recommendation No. 24:</b> explaining that “States parties should also, in particular . . . (e) Require all health services to be consistent with the human rights of women, including the rights to autonomy, privacy, confidentiality, informed consent and choice . . . .” Para. 31 (20th Session, 1999).</p> <p><b>CEDAW Committee:</b> recommending to <b>Zambia</b> that it “undertake awareness-raising campaigns throughout the state party and among personnel in multiple sectors of government in respect of the prevention, protection and maintenance of confidentiality in order to systemize and integrate approaches for combating HIV/AIDS.” CE-DAW/C/ZMB/CO/5-6 (CEDAW, 2011)</p>

**Table 5 (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 8(1):</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><b>ECHR 8(2):</b> There shall be no interference by a public authority with the exercise of this right except such is in accordance with the law and is necessary in a democratic in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p><b>ECtHR:</b> “As the spouse of a Russian national and father of a Russian child, the applicant was eligible to apply for a residence permit by virtue of his family ties to Russia . . . For his application to be completed, he needed to submit to HIV-testing and enclose a certificate showing that he was not infected with HIV . . . After the test revealed his HIV-positive status, his application for a residence permit was rejected on account of the absence of the mandatory HIV clearance certificate.” “Taking into account that the applicant belonged to a particularly vulnerable group, that his exclusion has not been shown to have a reasonable and objective justification, and that the contested legislative provisions did not make room for an individualised evaluation, the Court held that the applicant was a victim of discrimination on account of his health status in violation of Art. 14, taken together with Art. 8. <i>Kiyutin v. Russia</i>, 2700/10 (March 10, 2011).</p> <p><b>ECtHR:</b> The applicant’s HIV status was published in the newspaper claiming that the diagnosis was confirmed by the local hospital. The Court explained that “the Court has previously held that the protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention. Respecting the confidentiality of health data is a vital principle in legal systems of all Contract Parties to the Convention. The above considerations are especially valid as regards the protection of the confidentiality of a person’s HIV status.” The Court found that “State failed to secure the applicant’s right to respect for her private life.” <i>Biriuk v. Lithuania</i>, 23373/03, para. 39 (November 25, 2008).</p> <p><b>ECtHR:</b> “In her application to the Commission the applicant complained, amongst other things, about the failure of the Finnish authorities to prevent the disclosure by the press of her identity and her medical condition as an HIV carrier . . . The Court thus reaches the conclusions that there has been no violation of Article 8 of the Convention (art. 8)(1) with respect to the orders requiring the applicant’s medical advisers to give evidence or (2) with regard to the seizure of her medical records and their inclusion in the investigation file. On the other hand, it finds (3) that making the medical data concerned accessible to the public as early as 2002 would, if implemented, give rise to a violation of Article (art. 8) and (4) that there has been a violation thereof (art. 8) with regard to the publication of the applicant’s identity and medical condition in the Court of Appeal’s judgment.” <i>Z v. Finland</i>, 22009/93, para. 62 (February 25, 1997).</p>

**Other Interpretations**

**Declaration on the Promotion of Patients’ Rights in Europe**, Art. 4.1: All information about a patient’s health status . . . must be kept confidential, even after death.

**Declaration on The Promotion of Patients’ Rights in Europe**, Art. 4.8: Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy .

**European Convention on Human Rights and Biomedicine**, Art. 10(1): Everyone has the right to respect for private life in relation to information about his or her health.

**Table 6: HIV, AIDS and freedom of expression and information**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Government censors HIV-prevention information directed at LGBT persons, sex workers, or people who use drugs on the grounds that it is obscene or promotes criminalized behavior.</li> <li>• Schools deny young people information about HIV and AIDS, safer sex, sexuality, or condoms.</li> <li>• Media reporting on HIV engages in stigma and stereotyping rather than providing factual information.</li> <li>• Government restricts a newspaper, website, or other communication by activists critical of government AIDS policies.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 13(1):</b> The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice.</p> <p><b>CRC 17:</b> States Parties recognize the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health.</p>	<p><b>CRC General Comment No. 4:</b> Providing numerous connections between the provisions of art. 13 and the right of children to access information regarding their health. CRC/GC/2003/4 (2003).</p> <p><b>CRC General Comment No. 3:</b> Has concluded that adolescent’s right to information about HIV and AIDS is part of the right to information. CRC/GC/2003/3, ¶4 (2003).</p> <p><b>CRC General Comment No. 3:</b> Finding that “[a]dequate measures to address HIV/AIDS can be undertaken only if the rights of children and adolescents are fully respected. The most relevant rights in this regard, in addition to those enumerated in paragraph 5 above, are the following: the right to access information and material aimed at the promotion of their social, spiritual and moral well being and physical and mental health (art. 17) . . . .”, CRC/GC/2003/3, ¶6 (2003).</p> <p><b>CRC:</b> Recommending that <b>Panama</b> “provide children with accurate and objective information about substance use, including hard drugs and tobacco, and protect children from harmful misinformation,” as well as to “strengthen its efforts to address adolescent health issues... [including those] to prevent and combat HIV/AIDS and the harmful effects of drugs.” CRC/C/15/Add.233 (2004).</p> <p><b>CRC:</b> Has expressed concern that <b>Estonia</b> is “increasing number of HIV-infections among injecting drug users” and encouraged the government “to continue its efforts to provide children with accurate and objective information about substance use”. CRC/C/15/Add.196 (2003).</p>

**Other Interpretations**

**SR Education:** Has noted the need for sexuality education in schools, as well as the need for schools to ensure the safety of gay and lesbian students.

**SR Freedom of Expression and Information:** Has commented on the abuse of the rights of sex workers and LGBT persons; noted restrictions on public speech and denial of HIV and AIDS information to these communities; noted the detention of persons in Kuwait because of a letter mentioning a lesbian relationship; and expressed concern in Uganda about the arrests and harassment of two gender-non-conforming women.

**Table 7: HIV, AIDS and freedom of assembly and association**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• State restricts formation of nongovernmental, community-based, or service organizations working on HIV and AIDS or imposes prohibitive bureaucratic requirements.</li> <li>• Police disperse a peaceful and authorized demonstration by AIDS activists.</li> </ul>

**Other Interpretations**

**Charter of Fundamental Rights of the European Union**

Art. 12(1): Everyone has the right to freedom of peaceful assembly and to freedom of association at all levels, in particular in political, trade union and civic matters, which implies the right of everyone to form and to join trade unions for the protection of his or her interests.

Art. 12(2): Political parties at Union level contribute to expressing the political will of the citizens of the Union.

**Table 8: HIV, AIDS and the right to marry and found a family**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• State requires HIV testing or proof of HIV-negative status as a condition of marriage.</li> <li>• State forces woman living with HIV to undergo abortion or sterilization, rather than providing her with information and services to prevent mother-to-child transmission of HIV.</li> <li>• Women are denied equal rights in marriage, divorce, or within families, thus decreasing their ability to negotiate safer sex or leave relationships that pose a risk of HIV.</li> <li>• State denies migrants the right to be accompanied by family members, thus increasing risk of HIV through casual sex.</li> <li>• State denies asylum to HIV-positive claimant while granting asylum to his or her family.</li> <li>• State removes child from household solely because parent(s) have HIV/AIDS.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 16:</b> States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations.</p>	<p><b>CEDAW Committee:</b> Recommending that <b>Kenya</b> “take appropriate action to eliminate all discriminatory laws, practices and traditions and ensure women’s equality with men particularly in marriage and divorce . . .” including through passage of HIV and AIDS legislation. Concluding Observations to Kenya, A/58/38 (2003).</p>



**Table 9: HIV, AIDS and the right to non-discrimination and equality**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A person is denied work, housing, medicine, or education due to actual or presumed HIV status.</li> <li>• A child affected by HIV faces discrimination because of his or her parents' HIV status.</li> <li>• Government-sponsored HIV-prevention materials exclude information targeted at certain minorities such as LGBT persons, persons with disabilities, or people who use drugs.</li> <li>• Discrimination in access to property and divorce render women more vulnerable to HIV.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 2(1):</b> Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</p>	<p><b>HRC:</b> Finding that <b>Jamaica</b> “should also ensure that persons living with HIV/AIDS, including homosexuals, have equal access to medical care and treatment.” CCPR/C/JAM/CO/3 (HRC, 2011)</p> <p><b>HRC:</b> Recommending to <b>Cameroon</b> that “public health programmes to combat HIV/AIDS should have a universal reach and ensure universal access to HIV/AIDS prevention, treatment, care and support.” CCPR/C/CMR/CO/4 (HRC, 2010)</p> <p><b>CHR:</b> Confirmed that the term “other status” in anti-discrimination provisions includes health status, including HIV status (1995 and 1996).</p>
<p><b>CRC 2:</b> States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child’s or his or her parent’s or legal guardian’s race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.</p>	<p><b>CRC:</b> Explaining the right to non-discrimination: “States parties have the obligation to ensure that all human beings below 18 enjoy all the rights set forth in the Convention without discrimination (art. 2), including with regard to ‘race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status’. These grounds also cover adolescents’ sexual orientation and health status (including HIV/AIDS and mental health). Adolescents who are subject to discrimination are more vulnerable to abuse, other types of violence and exploitation, and their health and development are put at greater risk. They are therefore entitled to special attention and protection from all segments of society.” General Comment No. 4, CRC/GC/2003/4, ¶6 (2003).</p> <p><b>CRC Committee:</b> observing of <b>Ukraine</b> that “the principle of non-discrimination with respect to . . . children living with HIV/AIDS . . . is not fully implemented in practice” and that there is a “lack of an express reference to the principle of non-discrimination with respect to the protection of children’s rights in domestic legislation.” CRC/C/UKR/CO/3-4 (CRC, 2011)</p> <p><b>CRC Committee:</b> in the context of anti-discrimination, recommended that <b>Kazakhstan</b> undertake awareness-raising and sensitization of legal and other professionals on the impact of HIV and AIDS on children (2006).</p> <p><b>CRC Committee:</b> Has recommended that States protect children from HIV-based discrimination in <b>Ukraine</b> (2011), <b>Angola</b> (2010), <b>Burundi</b> (2010), <b>Cameroon</b> (2010), <b>Paraguay</b> (2010), <b>Burkina Faso</b> (2010), <b>Tajikistan</b> (2010), <b>Mozambique</b> (2009), <b>Niger</b> (2009), <b>Mauritania</b> (2009), <b>Malawi</b> (2009), <b>Moldova</b> (2009), <b>Chad</b> (2009), <b>Bhutan</b> (2008), <b>Djibouti</b> (2008), <b>Uruguay</b> (2007).</p>

**Table 9 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 1:</b> For the purposes of the present Convention, the term “discrimination against women” shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.</p>	<p><b>CEDAW Committee:</b> Has made several recommendations on the elimination of discrimination against women in the context of HIV and AIDS (see Table 12, below).</p> <p><b>CEDAW Committee:</b> Recommending to <b>Singapore</b> “to review and repeal the law requiring a work - permit holder, including foreign domestic workers, to be deported on grounds of pregnancy or diagnosis of sexually transmitted diseases such as HIV/AIDS.” CEDAW/C/SGP/CO/4 (CEDAW, 2011)</p>
<p><b>ICERD 5:</b> States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights: (e)(iv) The right to public health, medical care, social security and social services.</p>	<p><b>CERD:</b> Expressed concern at the high rate of HIV and AIDS among minorities and ethnic groups and recommended that governments take appropriate action in <b>Estonia</b> (2006) and <b>South Africa</b> (2006 and 2003).</p>

**Other Interpretations****Select National Non-Discrimination Laws:**

United States: [www.ada.gov/aids/ada\\_aids\\_discrimination.htm](http://www.ada.gov/aids/ada_aids_discrimination.htm)

Australia: [www.afao.org.au/\\_data/assets/pdf\\_file/0011/4520/BPo6o6\\_Discrimination.pdf](http://www.afao.org.au/_data/assets/pdf_file/0011/4520/BPo6o6_Discrimination.pdf)

South Africa: <http://manuals.southernafricalitigationcentre.org/manual/equal-rights-all-litigating-cases-hiv-related-discrimination/chapter-5-comparative-law-releva>

**Table 10: HIV, AIDS and the right to the highest attainable standard of health**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• State fails to take progressive steps to ensure access to HIV-prevention information and services (e.g., condoms, sterile syringe programs, or voluntary counseling and testing) or imposes restrictions on such services.</li> <li>• State fails to take progressive steps to ensure access to anti-retroviral drugs, treatment for opportunistic infections, opioid pain medications for palliative care, or comprehensive TB care.</li> <li>• State fails to ensure that sex workers, MSM, prisoners, people who use drugs and other vulnerable groups enjoy proportionate access to HIV prevention, treatment, and care services.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p> <p><b>ICESCR 12(2):</b> The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases</p>	<p><b>CESCR: Art. 12</b> includes “the right to prevention, treatment and control of epidemic... diseases,” including HIV. Recommendations include: <b>Georgia</b> to undertake general HIV-prevention measures (2002); <b>Moldova</b> to “intensify efforts” on HIV (2003); <b>Russia</b> to take “urgent measures to stop the spread of HIV” and related discrimination (2003); <b>Ukraine</b> to provide HIV information to adolescents (2001).</p> <p><b>CESRC:</b> Recommending that Kenya ensure that “[p]regnant women with HIV/AIDS are not refused treatment, segregated in separate hospital wards, forced to undergo HIV/AIDS testing, and discriminated or abused by health workers, and that they are informed about and have free access to antiretroviral medication during pregnancy, labour and after birth, including for their children.” E/C.12/KEN/CO/1 (CESCR, 2008)</p>

**Table 10 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(1):</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p><b>CRC Committee:</b> Recommended that <b>Russia</b> study its practice of “segregating children of HIV-positive mothers in hospital wards or separate orphanages and of HIV positive children being refused access to regular orphanages, medical care and educational facilities.” CRC/C/RUS/CO/3 (2005)</p> <p><b>CRC Committee:</b> Has recommended that States improve HIV-prevention services for children, protect children from HIV-based discrimination, and include children’s rights in HIV strategies. See, for example, comments on <b>Belarus</b> (2011), <b>Panama</b> (2011), <b>Ukraine</b> (2011), <b>Angola</b> (2010), <b>Grenada</b> (2010), <b>Nigeria</b> (2010), <b>Malawi</b> (2009), <b>Bhutan</b> (2008), <b>Eritrea</b> (2008), <b>Mali</b> (2007), <b>Benin</b> (2006), <b>Senegal</b> (2006), <b>Swaziland</b> (2006), <b>Nigeria</b> (2005), <b>Uganda</b> (2005), <b>Armenia</b> (2004), <b>Burkina Faso</b> (2002), <b>Mozambique</b> (2002), <b>Kenya</b> (2001), <b>Georgia</b> (2000), <b>Tajikistan</b> (2000), and <b>South Africa</b> (2000).</p>
<p><b>CEDAW 12(1):</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p>	<p><b>CEDAW Committee:</b> Recommending that <b>Zambia</b> “improve access to free prevention, treatment and care and support services at the programming level where gender and customary factors contribute significantly to infection rates among women and girls” and “improve access to services for HIV-positive women by incorporating gender-based violence concerns into health-care protocols and introducing measures to effectively respond to gender-based violence and abuse.” CEDAW/C/ZMB/CO/5-6 (CEDAW, 2011)</p> <p><b>CEDAW Committee:</b> recommending that <b>Ethiopia</b> “provide free antiretroviral treatment for women and men living with HIV/AIDS, including pregnant women, so as to prevent mother-to-child transmission; train technical and administrative staff to implement the national multisectoral strategy/action framework to combat HIV/AIDS and adopt prevention programmes targeting high-risk groups , such as young women, sex workers and internally displaced persons; conduct awareness-raising activities to de stigmatize orphans and vulnerable children affected by HIV/AIDS and strengthen the material and psychological support provided to them.” CEDAW/C/ETH/CO/6-7 (CEDAW, 2011)</p>

**Other Interpretations**

**The Declaration on the Promotion of Patients’ Rights in Europe, Art. 5.3:** Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider.

**WHO 1978 Declaration of Alma-Ata:** The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

**World Health Organization Constitution, Preamble:** The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

**Charter of Fundamental Rights of the European Union, Art. 35:** Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all the Union’s policies and activities.

**The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT 2001), Para 33:** The provision of basic necessities of life must always be guaranteed in institutions where the State has persons under its care and/or custody. These include adequate food, heating and clothing as well as, in health establishments, appropriate medication.

**Table II: HIV, AIDS and the rights of women and children**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Women are denied access to a full range of health services, including reproductive health care, to prevent and mitigate the impact of HIV for themselves and their children.</li> <li>• Children are denied access to comprehensive HIV-prevention services and information.</li> <li>• Children orphaned or affected by AIDS are withdrawn from school, denied their inheritance, and forced into hazardous situations such as forced labor, begging, and sexual exploitation.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(1):</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p><b>CRC:</b> Recommending that <b>Myanmar</b> “increase its efforts to prevent the spread of HIV/AIDS, with an emphasis on prevention among young people, provide protection and support for orphans and vulnerable children, and ensure universal and cost-free access to antiretroviral therapy.” CRC/C/MMR/CO/3-4 (CRC, 2012)</p> <p><b>CRC:</b> Recommending that <b>Azerbaijan</b> “intensify efforts to provide adolescents with education on sex and reproductive health, particularly with regard to HIV, and improve the accessibility of contraception.” CRC/C/AZE/CO/3-4 (CRC, 2012)</p> <p><b>CRC:</b> Recommending to <b>Togo</b> “to increase both the coverage and quality of PMTCT services in order to attain the objective of virtually eliminating mother-to-child HIV transmission by 2015” and “to reinforce preventive action among youth, targeting teenagers that belong to the most vulnerable groups, and ensure that the necessary budget is allocated to the HIV/AIDS education programme provided in secondary schools.” CRC/C/TGO/CO/3-4 (CRC, 2012)</p> <p><b>CRC:</b> recommending to <b>Madagascar</b> and <b>Burundi</b> to improve prevention of mother-to-child transmission. CRC/C/MDG/CO/3-4 (CRC, 2012); CRC/C/BDI/CO/2 (CRC, 2010)</p> <p><b>CRC:</b> recommending <b>Panama</b> “undertake steps to reduce the greater risk of HIV/AIDS among indigenous children, including through the provision of culturally sensitive sex education and information on reproductive health, reduce the greater risk of HIV/AIDS among teenagers by providing reproductive health services especially aimed at them and by expanding their access to information on prevention of sexually transmitted diseases, and that it direct programmes at children with HIV/AIDS.” CRC/C/PAN/CO/3-4 (CRC, 2011)</p> <p><b>CRC:</b> Recommending that <b>Ukraine</b> (a) ensure effective implementation of the national HIV/AIDS programme 2009-2013 and the national strategic action plan for HIV prevention among children and by allocating adequate public funding and resources to these programmes; (b) to take all measures to implement the act on prevention of AIDS and social protection of the population, with special focus on respecting human rights of children and youth affected by HIV/AIDS or at risk of HIV/AIDS, including children in street situations and children suffering from substance abuse, and ensure access to confidential and youth-friendly services; and (c) to intensify information and awareness campaigns on HIV/AIDS and other sexually transmitted diseases, aimed at adolescents as well as at the general public. CRC/C/UKR/CO/3-4 (CRC, 2011)</p> <p><b>CRC:</b> recommending <b>Belarus</b> and <b>Guatemala</b> implement youth-friendly HIV testing and counselling. CRC/C/BLR/CO/3-4 (CRC, 2011); CRC/C/GTM/CO/3-4 (CRC, 2010).</p> <p><b>CRC:</b> recommending increasing awareness and education about HIV/AIDS to <b>Sudan</b> CRC/C/SDN/CO/3-4 (CRC, 2010); <b>Belarus</b> CRC/C/BLR/CO/3-4 (CRC, 2011); <b>Montenegro</b> CRC/C/MNE/CO/1 (CRC, 2010); <b>Angola</b> CRC/C/AGO/CO/2-4 (CRC, 2010); <b>Sri Lanka</b> CRC/C/LKA/CO/3-4 (CRC, 2010); <b>Burundi</b> CRC/C/BDI/CO/2 (CRC, 2010); <b>Grenada</b> CRC/C/GRD/CO/2 (CRC, 2010); <b>Nigeria</b> CRC/C/NGA/CO/3-4 (CRC, 2010); <b>Japan</b> CRC/C/JPN/CO/3 (CRC, 2010); <b>Cameroon</b> CRC/C/CMR/CO/2 (CRC, 2010); <b>El Salvador</b> CRC/C/SLV/CO/3-4 (CRC, 2010); etc.</p>

**Table II (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 12(1):</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p> <p><b>CEDAW 12(2):</b> Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.</p>	<p><b>CEDAW Committee:</b> Explaining to <b>Zambia</b> that the “Committee is concerned about the impact of HIV/AIDS on women and especially own young girls who are raped due to the belief that intercourse with a virgin cures the infection. In this respect, the Committee is concerned that women and girls may be particularly susceptible to infection owing to gender-specific norms and that the persistence of unequal power relations between women and men and the inferior status of women and girls may hamper their ability to negotiate safe sexual practices, thereby increasing their vulnerability to infection.” CEDAW/C/ZMB/CO/5-6 (CEDAW, 2011)</p> <p><b>CEDAW Committee:</b> Recommending that <b>Russia</b> “address gender aspects of HIV/AIDS, including power differential between women and men, which often prevents women from insisting on safe and responsible sex practices.” A/57/38(SUPP) (CEDAW, 2002)</p>
<p><b>ICESCR 2(2):</b> The States Parties to the present Covenant undertake to guarantee that the right enunciated in the present Covenant will be exercised without discrimination of any kind as to . . . sex . . .</p> <p><b>ICESCR 3:</b> The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.</p>	<p><b>CESCR:</b> Recommending that <b>Kenya</b> ensure that “pregnant women with HIV/AIDS are not refused treatment, segregated in separate hospital wards, forced to undergo HIV/AIDS testing, and discriminated or abused by health workers, and that they are informed about and have free access to antiretroviral medication during pregnancy, labour and after birth, including for their children.” E/C.12/KEN/CO/1 (CESCR, 2008)</p> <p><b>CESCR:</b> Noting with concern that children and orphans affected by HIV/AIDS in <b>Kenya</b> are not adequately supported by the State party and that the care for these children and the task of monitoring their school attendance is frequently delegated to their extended families and to community and faith-based organizations, without adequate support and supervision from the State party. E/C.12/KEN/CO/1 (CESCR, 2008)</p>

### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>188</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>189</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>190</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>191</sup>

<sup>188</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>189</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>190</sup> Ibid.

<sup>191</sup> Ibid.



A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>192</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

<sup>192</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## 4. SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF HIV, AIDS AND HUMAN RIGHTS?

This section contains **eight examples** of effective activities in the area of HIV, AIDS, and human rights. These are:

1. Litigating for universal access to medicines under the right to health;
2. Combating legislation criminalizing HIV transmission;
3. Documenting effective HIV policies and programs for women and girls;
4. Using litigation to protect HIV-positive women from coerced sterilization;
5. Using medical-legal partnerships to promote the rights of people living with HIV;
6. Using constitutional rights to equal protection to fight against employment discrimination of those living with HIV; and
7. The Now More Than Ever Campaign.
8. Strategic litigation to protect the rights of women forcibly sterilized in Namibia.

## Example I: Litigating for universal access to medicines under the right to health

***Minister of Health v. Treatment Action Campaign 2002 (5) SA 721 (CC) ( S. Afr.).***

[www.saflii.org/cgi-bin/disp.pl?file=za/cases/ZACC/2002/15.html&query=%20treatment%20action%20campaign](http://www.saflii.org/cgi-bin/disp.pl?file=za/cases/ZACC/2002/15.html&query=%20treatment%20action%20campaign)

### **Project Type**

Litigation

### **The Organization**

The Treatment Action Campaign (TAC) is a 16,000-member strong civil society organization founded on December 10, 1998 in Cape Town, South Africa. TAC is committed to increasing access to treatment, care and support programs for people living with HIV and also works to spread information and strategies for reduces the transmission of HIV. In 2004, TAC won the Nobel Peace Prize for their efforts.

The AIDS Law Project (ALP), founded in 2007 by dedicated public interest lawyers, is a nongovernmental organization seeking justice and equal treatment for those living with HIV. The AIDS Law Project provides a range of programs and services related to legal services, human rights and health; policy advocacy and communication; and capacity strengthening.

### ***Violations of the South African Bill of Rights***

**Section 27(1):** Everyone has the right to have access to (a) health care services, including reproductive health care.

**Section 27(2):** The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights.

**Section 28(1):** Every child has the right . . . (c) to basic nutrition, shelter, basic health care services and social services.

Southern Africa Legal Information Institute.

[www.saflii.org/cgibin/disp.pl?file=za/legis/num\\_act/cotrosa\\_1996423/cotrosa1996423.html&query=-constitution](http://www.saflii.org/cgibin/disp.pl?file=za/legis/num_act/cotrosa_1996423/cotrosa1996423.html&query=-constitution)

### **The Problem**

Treatment to reduce the likelihood of mother-to-child transmission of HIV was unavailable to the vast majority of women who needed it in South Africa. In 2001, it was estimated that approximately 70,000 children would become infected with HIV through mother-to-child transmission. Although treatment with azidothymidine (AZT) or Nevirapine can significantly reduce the risk of HIV transmission from mother to child, in 2001 the South African government was restricting this treatment to two pilot sites in each province.

### Procedure

In 2001, Treatment Action Campaign (TAC) and the AIDS Law Project (ALP) brought a suit in the High Court in Pretoria to secure access to medication for pregnant women to reduce mother-to-child transmission of HIV. The high court found for TAC and held that the South African Constitution required the government to make Nevirapine available to HIV-positive pregnant women who give birth in public health facilities; the women's babies were also to receive the medication. The Court also held that the Constitution required the Government to formulate and implement a national health program to reduce the transmission of HIV from mother to child. The Government appealed the decision of the high court to the Constitutional Court.

### Arguments and Holdings

TAC challenged the Government based on section 27 of the South African Bill of Rights, which protects "the right to have access to health care services." TAC claimed that the Government could not refuse to make Nevirapine, a registered drug, available to pregnant women with HIV who give birth in a public hospital or clinic. Moreover, TAC claimed that the government had a constitutional duty to create and implement a national program to prevent mother-to-child transmission of HIV.

The Constitutional Court set aside the orders of the high court and ordered the government to remove restrictions on Nevirapine to permit its use in public health facilities. The Court also held that counsellors should be provided at public hospitals and clinics for training and use of Nevirapine, if necessary. Finally, the Court held that the government should take reasonable measures to extend the testing and counselling facilities at hospitals and clinics throughout the public sector.

### Commentary and Analysis

In addition to a strong litigation strategy, there were several other factors that contributed to the success of the litigation. These included:

- A broad social movement accompanying the litigation;
- Charismatic and committed leadership on the part of people living with HIV;
- Alliances with treatment activists around the world;
- The existence of a constitutional democracy with independent courts and a constitution protecting health rights; and
- A legacy of public interest litigation dating back to the post-apartheid era.

This victory was a significant achievement for activists advancing social and economic rights. Traditionally, claims based on the right to health have not been successful in litigation and so this case marked a new era in health and human rights litigation. Health rights activists are now strategically using constitutional provisions to secure health right victories to instigate legal and policy changes.

### Additional Resources

There are several wonderful resources to aide health right activists to understand the advances in right to health litigation and to help develop litigation strategies:

Yamin AEY and Gloppen S, eds., *Litigating Health Rights: Can Courts Bring More Justice to Health?* (2011)

Meier BM and Yamin AEY, *Right to Health Litigation and HIV/AIDS Policy*, 39 *Journal of Law, Medicine & Ethics* (Spring 2011).

Gloppen S, *Litigation as a Strategy to Hold Governments Accountable for Implementing the Right to Health*, 10 *Health and Human Rights: An International Journal*, no. 2, 2008. [www.hhrjournal.org/index.php/hhr/article/viewFile/79/145](http://www.hhrjournal.org/index.php/hhr/article/viewFile/79/145).

## Example 2: Combating legislation criminalizing HIV transmission

### Project Type

Advocacy

### The Organization

The Canadian HIV/AIDS Legal Network is an international organization that promotes the human rights of people living with and vulnerable to HIV through research, analysis, advocacy, litigation, public education, and community mobilization.

### Africa National statutes criminalizing the spread of HIV

**Adopted:** Burundi (2005), Djibouti (2007), Kenya (2006), Madagascar (2005), Mozambique (2009) and Tanzania (2008), Cameroon (2002), Chad (2007), Congo (2009), Democratic Republic of Congo (2008), Equatorial Guinea (2006), Benin (2006), Burkina Faso (2008), Cape Verde (2008), Guinea (2005), Guinea-Bissau (2007), Liberia (2008), Mali (2006), Mauritania (2007), Niger (2007), Sierra Leone (2007), Togo (2005), Lesotho (2003), Zimbabwe (2001).

**Proposed:** Malawi, Uganda, Botswana. Status Unclear: Angola (2004), Central African Republic (2006), Senegal (2010).

### Africa: National statutes criminalizing the spread of a deadly disease

**Adopted:** Ethiopia, Botswana.

**Proposed:** Rwanda.

Source: NAM: [www.aidsmap.com/](http://www.aidsmap.com/)

### The Problem

A model law on HIV transmission was drafted following a meeting held in N'Djamena, Chad in 2004 by Action for West Africa Region—HIV/AIDS (AWARE), with funding from the United States Agency for International Development (USAID). The model law expands criminal liability for intentional transmission of HIV. Over 25 African countries now criminalize wilful transmission of HIV, including twelve countries in Western Africa that have adopted legislation based on the model law.

The model law allows for radically expanded criminal liability for wilful transmission of HIV by setting out a broad definition of “wilful transmission” and by demanding punishment for all wilful transmissions of the virus. Article 36 of the model law sets out that “any person who is guilty of wilful transmission of HIV shall be sanctioned . . . .” The article broadly defines “wilful transmission” as “transmission of the HIV virus through any means by a person with full knowledge of his/her HIV/AIDS status to another person.” Therefore, the model law would expand criminal liability to include, inter alia, mother-to-child transmission; transmission between consenting parties engaging in safe sex; and the transmission that results from the sharing of needles for injection drug use, even after attempts have been made to disinfect.

### Actions Taken

The Canadian HIV/AIDS Legal Network (CHLN), along with other concerned NGOs, worked to raise public awareness of the effects of this model law. In addition, the CHLN pressed UNAIDS to publish an alternative model law. CHLN provided legal analysis and aided the drafting of various provisions of the alternative model law. UNAIDS later published the alternative model law as part of its materials, and domestic NGOs used the alternative model law to try to reform criminalization provisions that had passed or were pending adoption. The alternative model law was designed for policy makers and advocates in developing countries where legislative drafting resources may have been scarce.

### Results & Lessons Learned

HIV prevention, care and treatment services operate best within a clear legal framework. Law reform is not a complete solution, but it is a necessary and often neglected step. Reforming law and policy around the issue of HIV can be especially challenging given the stigma and discrimination in the general population against those living with HIV and competing demands on the time and energy of local advocates.

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### Additional Resources

Richard Pearshouse, *Canadian HIV/AIDS Legal Network, A Human Rights Analysis of the N'Djamena Model Legislation on AIDS and HIV-specific Legislation in Benin, Guinea, Guinea-Bissau, Mali, Niger, Sierra Leone and Togo* (September 2007). [www.aidslaw.ca/publications/publicationsdocEN.php?ref=967](http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=967).

Cécile Kazatchkine et al, *Canadian HIV/AIDS Legal Network, Criminalizing HIV Transmission or Exposure in the Context of West and Central French-speaking Africa* (2010). [www.aidslaw.ca/EN/aids2010/documents/AIDS10\\_CK\\_Africa.pdf](http://www.aidslaw.ca/EN/aids2010/documents/AIDS10_CK_Africa.pdf).

*Legislation contagion: building resistance*, 13 *Canadian HIV/AIDS Legal Network: HIV/AIDS Policy & Law Review*, no. 2/3 (December 2008). [www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1412](http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1412).

NAM, *The 'Legislation Contagion' of the N'Djamena Model Law*. [www.aidsmap.com/page/1442068/](http://www.aidsmap.com/page/1442068/).

Pearshouse R., *Legislation contagion: the spread of problematic new HIV laws in Western Africa*. *HIV/AIDS Policy & Law Review* 12 (2/3), 2007.

Pearshouse R., *Legislation contagion: building resistance*. *HIV/AIDS Policy & Law Review* 12 (2/3), 2008.

**Canadian HIV/AIDS Legal Network**  
 Toronto, Canada  
 Website: <http://www.aidslaw.ca>  
 E-mail: [info@aidslaw.ca](mailto:info@aidslaw.ca)



## Example 3: Documenting effective HIV policies and programs for women and girls

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### Project Type

Advocacy

### The Organization

*What Works for Women & Girls* is a comprehensive website documenting the evidence for effective HIV interventions to guide donors, policymakers, and program managers in planning effective HIV policies and programs for women and girls. The resource spans nearly 3,000 reports and articles with more than 450 interventions in nearly 100 countries. ([www.whatworksforwomen.org](http://www.whatworksforwomen.org))

*What Works* has been a collaborative effort. It was originally funded by the Open Society Foundations' Public Health Program. Currently, it is supported by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and Open Society Foundations. It is carried out under the auspices of the United States Agency for International Development (USAID)-supported Health Policy Project at the Futures Group, in collaboration with the Public Health Institute.

The three primary authors of the *What Works* report bring a unique set of research, gender and communication expertise that enable the resource to be both technically rigorous and widely accessible. Moreover, each of the sections of *What Works* underwent extensive peer review from experts in the respective areas, ensuring that all of the key literature was included and put into context. The massive undertaking of creating *What Works* across the spectrum of HIV topics would not have been possible without the more than 100 experts in research, programming and advocacy.

### The Problem

Women are disproportionately affected by the HIV epidemic. For example, women make up more half or more of those living with HIV and young women 15-24 years old are as much as eight times as likely as men to be living with HIV in sub-Saharan Africa – the region most affected by HIV (UNAIDS, 2010). In the context of HIV, women face unique risks and have diverse needs influenced by their physical and social environment. Transforming gender norms; advancing education, employment and women's legal rights; and reducing stigma, discrimination, and violence against women remain urgent priorities in HIV programming.

Awareness of the vulnerability of women and girls to HIV is only the first step. Identifying and implementing HIV programs that address the particular vulnerabilities of women and girls is the next step. When designing HIV and AIDS programs, policymakers and program planners have scarce resources and encounter a wide array of statistics, recommendations, best practices, scientific studies, and public health interventions. Policymakers and programmers have been forced, at best, to undertake their own research to identify effective programming and, at worst, to base policies and programs on unquestioned practices. Until now, there has not been one central location to obtain been a clear universal understanding of what works for women and girls.

**Actions Taken**

*What Works* makes gender sensitive HIV resources more widely available by providing a one-stop resource center. Through a comprehensive literature review of published work and gray literature, the *What Works* team reviews the evidence and distils successful interventions from that evidence. Written in clear language with policymakers and program planners in mind, *What Works* outlines the interventions that have been proven to work for women and girls, thus providing the evidence base for those designing policies and programs. It also demonstrates the significant gaps in programming for which there are few, if any, evaluated data, thus serving to spur researchers and implementers to design and evaluate additional programming for women and girls. *What Works for Women and Girls* helps maximize the efficiency and effectiveness of HIV programs by providing, in one place, evidence of successful and promising approaches and interventions. In the words of one advocate, “*What Works is absolutely the bottom line...*”

*What Works for Women & Girls* is available free online, with flash drives of static copies available for those with unreliable internet service, thus putting the evidence into the hands of those who cannot access or afford costly database subscriptions. Outreach efforts to provide technical assistance are underway to achieve the goal of becoming the leading go-to source of evidence on HIV interventions for women and girls, with health and gender ministries, implementing agencies, NGOs, and advocates using the evidence to develop women-friendly, gender transformative HIV policies and programs around the world.

**Lessons Learned**

HIV programs and policies must be based on evidence and *What Works for Women and Girls* provides the available evidence. *What Works* points out clear interventions that work for women and girls and highlights the supporting evidence. The interventions were not pre-defined with supporting evidence sought. Instead, interventions emerged from the literature reviews. Both authors and experts were at times surprised that almost 30 years into the epidemic, numerous studies do not disaggregate data by sex or consider gender. *What Works* also demonstrates the need for more evaluation and measurement of innovative programs to add to the list of what works for women and girls. As a resource, *What Works for Women & Girls* can guide effective, evidence-based programming, and highlight what remains to be done to address the needs of women and girls.

Website: <http://www.whatworksforwomen.org/>

## Example 4: Using litigation to protect HIV-positive women from coerced sterilization

*L M and Others v. The Government of the Republic of Namibia (July 30, 2012).*

### Project Type

Litigation

### The Organization

Southern Africa Litigation Centre (SALC) provides technical assistance and financial backing to public and private lawyers, civil society organizations and community-based organizations pursuing the public interest through impactful litigation. Strategic litigation, like that undertaken by SALC, can help level the playing field. Through litigation, the SALC challenges existing laws and regulations and pursues progressive legal reform through judicial decision-making. In addition to securing justice for their clients and others similarly situated, the SALC's efforts draw public attention to the issues faced by those they represent.

### The Problem

Discrimination against people living with HIV stymies efforts to reduce morbidity and increase access to HIV prevention and treatment. Many people living with HIV often face economic hardship, violence and social stigma, contributing to an increased risk of human rights abuses. Legal remedies for discrimination against people living with HIV are often difficult to obtain. In Namibia, people living with HIV do not have full access to justice, due in part to a lack of access to legal services, a legal system with pervasive corruption and lack of knowledge of individual rights.

"I have been taught to be quiet. It would be helpful if someone could come and speak on my behalf."  
 – **Esther K. of Chilumba, Malawi** (Chi Mgbako et al, *We Will Still Live*, 31 *Fordham International Law Journal* 528, 583 (Jan. 2008)).

Coerced sterilization is a common practice in countries with high rates of HIV infection. Coerced sterilization is defined as any procedure performed on a man or women without their informed consent that eliminates their ability to have children. Doctors at government hospitals in Namibia continue to sterilize HIV-positive women without their informed consent. A 2009 study by the International Community of Women Living with HIV/AIDS found that, of those surveyed, nearly one out every five women living with HIV in Namibia has been subjected to coerced sterilization. Coerced sterilization violates a women's bodily integrity and reproductive rights. Moreover, for women in Namibia, sterilization can lead to additional exclusion, social stigma and restricted marriage prospects.

### Actions Taken

With the help of the SALC, three HIV-positive Namibian women who were victims of coerced sterilization at a government hospital brought a common law and constitutional tort action against the government for money damages and injunctive relief.

**Results and Lessons Learned**

On July 30, 2012, the Namibian High Court ruled that the three women had been sterilized without their consent and therefore coerced into sterilization. Although the court did not rule on the constitutional claim or whether the women were selected for sterilization based on their HIV-positive status, the court did determine that the government owed the plaintiffs money damages. As noted by Nicole Fritz, director of SALC, “The court’s detailed ruling as to what constitutes informed consent upholds the rights of the plaintiffs, recognises their entitlement to redress and lessens the vulnerability to which women especially are likely to be subject [to coerced sterilization].” Priti Patel, the deputy director of SALC, noted that this case means that authorities in Namibia “must [now] meaningfully investigate all the other cases to ensure justice for every woman who has been coercively sterilised.”

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**Additional Resources**

The Guardian (U.K.): Namibia court rules HIV-positive women sterilised without consent.

[www.guardian.co.uk/global-development/2012/jul/30/namibia-hiv-women-sterilised-without-consent](http://www.guardian.co.uk/global-development/2012/jul/30/namibia-hiv-women-sterilised-without-consent)

Mindy Roseman: The Day After Victory: More Work Needed to Protect Rights of Namibian Women Living with HIV. <http://harvardhumanrights.wordpress.com/2012/07/1/the-day-after-victory-more-work-needed-to-protectrights-of-namibian-women-living-with-hiv/>

The International Community of Women Living with HIV/AIDS (ICW), *The Forced and Coerced Sterilization of HIV Positive Women in Namibia* (2009). [www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf](http://www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf)

**South African Litigation Centre (SALC)**

Johannesburg, South Africa

E-mail: [Enquiries@salc.org.za](mailto:Enquiries@salc.org.za)

Website: <http://www.southernafricalitigationcentre.org/>

## Example 5: Using medical-legal partnerships to promote the rights of people living with HIV

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### Project Type

Advocacy

### The Organizations

The Legal Aid Centre of Eldoret (LACE) and the Christian Health Association of Kenya (CHAK) are closely related in purpose and organization. Founded in 2008 by Kenyan attorneys and judges, LACE works to provide access to justice for those living with HIV in Western Kenya. In similar fashion, the Christian Health Association of Kenya (CHAK) comprises 435 member health facilities throughout Kenya, 15 of which provide not only health services but also rights awareness and legal services to their clients. Both organizations work to provide health and human rights to those living with HIV in western Kenya.

### The Problem

An estimated 1.4 million people live with HIV in Kenya and they face stigmatization, discrimination, derogatory stereotypes, and pervasive prejudice. As a result, people living with HIV experience legal issues related to the denial of property rights, criminal charges, unfair dismissal, breach of confidentiality, physical and sexual abuse, and child support payment disputes.

### Actions Taken

LACE (The Legal Aid Centre of Eldoret): Health care workers at the Academic Model Providing Access to Healthcare (AMPATH) office in western Kenya have training to recognize legal problems expressed by their patients. When a legal issue arises, the medical workers refer their patients to LACE, which occupies an office directly across the street from the AMPATH office. The LACE attorneys refer the patients to pro bono attorneys practicing in the area or the pro bono legal clinic at Moi University School of Law. Clients also receive referrals for psychosocial support services. Once their legal needs are addressed, they are referred back to AMPATH social workers.

CHAK (Christian Health Association of Kenya): CHAK and the Kenya Episcopal Conference health facilities account for approximate 40% of all health service providers in Kenya. CHAK's attorney travels regularly to 15 of CHAK's health facilities to train health care workers to recognize human right violations. The lawyer also works with community leaders to foster the creation of community organizations that monitor and report human rights violations.

### Results and Lessons Learned

LACE: LACE combats the so-called “third epidemic” of HIV—the economic, social, and cultural effects HIV has on a community and on individuals. By working closely with AMPATH, an established health care provider, LACE receives a high volume of clients and is able to address the health and human rights abuses of those often-marginalized people who live with HIV. In 2009, LACE counselled 336 HIV-positive clients.

CHAK: In 2011, CHAK received 198 cases, most of which they referred to lawyers at partner organizations. CHAK’s legal officer emphasizes the need to work closely with community opinion leaders, as they are critical in responding to most HIV-related human rights violations. She also recommends carrying out an initial needs assessment and identifying stakeholders for partnership because it is not possible for one organization to address all of the community’s needs.

#### **Legal Aid Center of Eldoret (LACE)**

Eldoret, Kenya

E-mail: [info@lancelaw.org](mailto:info@lancelaw.org)

Website: [lancelaw.org](http://lancelaw.org)

#### **Christian Health Association of Kenya (CHAK)**

Nairobi, Kenya

Website: [www.chak.or.ke](http://www.chak.or.ke)

## Example 6: Using constitutional rights to equal protection to fight against employment discrimination of those living with HIV

**India: *MX v. ZY*, AIR 1997 Bom 406 (High Court of Judicature, 1997).**

<http://indiankanoon.org/doc/1264404/>.

**South Africa: *Hoffman v. South African Airways*, Constitutional Court of South Africa, Case CCT 17/00 (2000); 2001 (1) SA 1 (CC); 2000 (11) BCLR 1235 (CC).** [www.saflii.org/za/cases/ZACC/2000/17.html](http://www.saflii.org/za/cases/ZACC/2000/17.html).

### Project Type

Litigation

### The Organization

These two separate cases are both examples of individuals bringing successful human rights actions against their respective governments.

### The Problem

With the largest and second largest population of HIV-positive individuals in the world, South Africa and India experience high rates of employment discrimination on the basis of HIV status. However, both the South African and Indian constitutions provide for equal protection under the law. The two litigation case studies here show how equal protection—a constitutional guarantee in many countries—can protect individuals living with HIV from discrimination in the workplace.

In both cases, a public company terminated its relationship with an employee because of that employee's HIV-positive status. In *MX v. ZY* (India), the employer terminated its relationship with plaintiff-employee once it learned of that employee's HIV-positive status. In *Hoffman* (South Africa), the employer withdrew its offer of employment once it learned of the employee candidate's HIV-positive status.

### Arguments and Holdings

Both employees sued their public-corporation employer for violations of their respective country's constitutional equal protection provisions. In both cases, the public-corporation employer argued that it had "legitimate" reasons for terminating their relationship with their HIV-positive employee. In *MX v. ZY*, the employer argued that medical requirements were legitimate because of the added financial and administrative burdens associated with hiring an HIV-positive individual. In *Hoffman*, the public-employer also made business strategy arguments, including the undue cost of training an individual with a shorter lifespan and the unfair advantage that its private competitors—who may discriminate against individuals, unlike their government counterparts—would gain if they were forced to treat HIV-positive individuals equally. In both cases, the court rejected business strategy arguments, finding that the equal protection guarantees of the constitution trumped profit interests of the business.



In addition to business strategy arguments, the defendant in Hoffman argued that the ability of HIV-positive individuals may not be capable of performing essential job responsibilities. First, the defendant airline argued that the court should allow it to reject an applicant based on its HIV-positive status because the National Department of Health required international air cabin attendants to receive yellow fever vaccinations, which may be dangerous for HIV-positive individuals to receive. Second, the airline defendant argued that HIV-positive individuals may not be able to perform the responsibilities of an air cabin attendant during an emergency. The court rejected both these arguments, finding that equal protection demands that the employer perform individual assessments of each candidate's ability to perform essential job functions.

## Equal Protection

### Indian Constitution. Article 14:

The State shall not deny to any person equality before the law or the equal protection of the laws within the territory of India.

### South African Constitution. Section 9:

- (1) Everyone is equal before the law and has the right to equal protection and benefit of the law.
- (2) Equality includes the full and equal enjoyment of all rights and freedoms . . . . (3) The state may not unfairly discriminate directly or indirectly against any on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth. (4) No person may unfairly discriminate directly or indirectly against anyone on one or more ground in terms of subsections (3) . . . . (5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.

### Analysis and Commentary

Many of the world's constitutions provide for equal protection under the law. The two cases profiled here show how domestic equal protection guarantees can protect those living with HIV. In both cases, the courts found that a public corporation, bound by constitutional equal protection provisions, must assess individual candidates; a blanket rejection of HIV-positive individuals is in violation of an HIV-positive candidate's constitutional right to equal protection under the law.

People living with HIV are among the world's most vulnerable populations, facing widespread stigma and discrimination. Equal treatment requires government and state actor employers to individually assess each candidate. Policies discriminating on the basis of HIV status are not allowed.

## Example 7: Now More than Ever Campaign

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### Project Type

Advocacy

### The Organization

The Now More than Ever Campaign represents hundreds of AIDS activists worldwide who believe that human rights should be at the center of the response to HIV. It is their belief that if governments and organizations base their efforts upon human rights, the response will be more inclusive and effective.

“That virus is just as smart at exploiting social weakness as it is at exploiting the weaknesses of the immune system.” – **Jonathan Cohen**, Deputy Director, Open Society Public Health Program

### The Problem

Those most affected by HIV are often those who are marginalized by society. They include women and girls, children, people who use drugs, sex workers, men who have sex with men, transgender persons, prisoners, people needing palliative care, and others whose voices are rarely heard. The Now More Than Ever Campaign places particular emphasis on protecting members of these marginalized groups and believes that a human rights-based approach is necessary to the global response.

### Actions Taken

The campaign developed a joint statement on 10 reasons why human rights should occupy the center of the global HIV response. Since first publishing the joint statement, the Campaign has organized and led events at each successive International AIDS Conference. Information related to those events may be found at [www.hivhumanrightsnow.org/about-us/#overview](http://www.hivhumanrightsnow.org/about-us/#overview).

### Results and Lessons Learned

Over 650 organizations and networks worldwide have endorsed the joint statement, which is also supported by the United Nations Office of the High Commissioner for Human Rights (OHCHR), the United Nations Development Programme (UNDP), and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Additionally, tens of thousands of people participated in the campaign's protest march and rally for human rights in Vienna at the 2010 International AIDS Conference to call for human rights for all in the face of HIV—often expressing opinions that they could not legally express in their home country.

The Now More Than Ever Campaign brings together thousands of AIDS activists worldwide who believe that human rights should be at the center of the response to HIV. The campaign offers them a unique platform aimed at ensuring that governments move from rhetoric to real action on HIV and human rights, including by investing in key human rights initiatives as part of national HIV programs.

## Human Rights and HIV: Now More Than Ever

[www.hivhumanrightsnow.org/](http://www.hivhumanrightsnow.org/)

### *Ten Reasons Why Human Rights Should Occupy the Center of the Global AIDS Struggle*

1. Universal access will never be achieved without human rights;
2. Gender inequality makes women more vulnerable to HIV, most women and girls now have the highest rates of infection in heavily affected countries;
3. The rights and needs of children and young people are largely ignored in the response to HIV, even though they are the hardest-hit in many places;
4. The worst-affected receive the least attention in national responses to HIV;
5. Effective HIV-prevention, treatment, and care programs are under attack;
6. AIDS activists risk their safety by demanding that governments provide greater access to HIV and AIDS services;
7. The protection of human rights is the way to protect the public's health;
8. AIDS poses unique challenges and requires an exception response;
9. Rights-based" responses to HIV are practical, and they work;
10. Despite much rhetoric, real action on HIV/AIDS and human rights remains lacking.

Twenty-four HIV/AIDS and human rights organizations worldwide jointly developed the declaration, and hundreds of other organizations endorsed it. The declaration is also available in Arabic, Bulgarian, Chinese, French, German, Portuguese, Romanian, Russian, and Spanish.

### **Human Rights and HIV: Now More Than Ever**

Website: <http://www.hivhumanrightsnow.org/>

## 5. WHERE CAN I FIND ADDITIONAL RESOURCES ON HIV/AIDS AND HUMAN RIGHTS?

The most comprehensive collection of resources on HIV and human rights is contained in an e-Library at AIDSLEX: [www.aidslex.org](http://www.aidslex.org). This resource is available online and in six different languages. This e-Library is a comprehensive repository of materials on HIV, law, and human rights. UNAIDS also has a large collection of UN and WHO documents available for download on its website, [www.unaids.org](http://www.unaids.org). Resources are categorized according to the 2011 Political Declaration targets and elimination commitments.

A list of commonly used resources on HIV, AIDS and human rights follows organized according to key topics highlighted within the text. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Statements and Declarations
- D. General Resources
- E. Non-Discrimination and Equality
- F. Right to Marry and Right to Found a Family
- G. Right to Privacy
- H. Freedom of Liberty of Movement
- I. Freedom of Expression and Information
- J. Right to Health and Right to the Enjoyment of the Benefits of Scientific Progress
- K. Right to Adequate Standard of Living and Social Security
- L. Right to Work
- M. Women and HIV
- N. Children and HIV
- O. Criminalization of HIV Exposure and Transmission
- P. Key Populations – People who use drugs
- Q. Key Populations – Sex Workers
- R. Key Populations – LGBTQ & MSM
- S. Key Populations – Prisoners
- T. Key Populations – People with Disabilities
- U. Key Populations – Refugees and Internally Displaced Persons\
- V. Journals
- W. Blogs and Listservs
- X. Training Manuals
- Y. Websites

## A. International Instruments

All resources in this section available at OHCHR, “Publications and Documents on HIV and AIDS”, ([www.ohchr.org/EN/Issues/HIV/Pages/Documents.aspx](http://www.ohchr.org/EN/Issues/HIV/Pages/Documents.aspx)), unless otherwise indicated. Available in multiple languages.

### Nonbinding

- International Labor Organization, *Code of Practice on HIV/AIDS and the World of Work* (June 1, 2001).
- International Labor Organization, *Recommendation concerning HIV and AIDS and the World of Work*, No. 200 (2010).
- UN, Standard Minimum Rules for the Treatment of Prisoners (August 30, 1995). [www1.umn.edu/humanrts/instreet/g1smr.htm](http://www1.umn.edu/humanrts/instreet/g1smr.htm)
- UN Commission on the Status of Women, *Women, the girl child and HIV/AIDS*. Resolutions 47/1 (2003), 50/2 (2006), 53/2 (2009), 55/2 (2011).
- UN Committee on the Elimination of Discrimination against Women, *General Recommendation No. 15: Women and AIDS* (1990). [www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recom15](http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recom15)
- UN Committee on Economic, Social and Cultural Rights, *General Comment no. 20: Nondiscrimination in Economic, Social and Cultural Rights*, E/C.12/GC/20 (2009). <http://tb.ohchr.org/default.aspx?Symbol=E/C.12/GC/20>
- UN Committee on the Rights of the Child, *General Comment no. 3: HIV/AIDS and the Rights of the Child*, CRC/GC/2003/3 (2003). <http://tb.ohchr.org/default.aspx?Symbol=CRC/GC/2003/3>
- UN Committee on the Rights of the Child, *General Comment no. 4: Adolescent Health*, CRC/GC/2003/4 (2003). <http://tb.ohchr.org/default.aspx?Symbol=CRC/GC/2003/4>
- UN General Assembly, *Declaration of Commitment on HIV/AIDS*, A/RES/S-26/2 (June 27, 2001).
- UN General Assembly, *Political Declaration on HIV/AIDS*, A/RES/60/262 (June 15, 2006).
- UN General Assembly, *Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS*, A/RES/65/277 (July 8, 2011).
- UN Human Rights Council, *Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria*. Decision 2/107 (2006).
- UN Human Rights Council, *Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria*. Resolutions 2003/29 (2003), 2004/26 (2004), 2005/23 (2005).
- UN Human Rights Council, *Access to medicines in the context of right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Resolutions 12/24 (2009), 17/14 (2011).
- UN Human Rights Council, *Rights of the child*. Resolution 2004/48 (2004).
- UN Human Rights Council, *The right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Resolutions 2004/27 (2004), 6/29 (2007), 15/22 (2010).
- UN Human Rights Council, *The protection of human rights in the context of HIV and AIDS*. Resolutions 16/28 (1997), 1997/33 (1997), 1999/49 (1999), 2001/51 (2001), 2003/29 (2003), 2003/47 (2003), 2004/26 (2004), 2005/23 (2005), 2005/84 (2005), 12/27 (2009), 16/28 (2011).
- UN Security Council, *Children in armed conflict*. Resolution 1460 (2003).

- UN Security Council, *HIV and peacekeeping*. Resolution 1983 (2011).
- UN Security Council, *HIV/AIDS and peacekeeping*. Resolution 1308 (2000).
- WHO, *A Declaration on the Promotion of Patients' Rights in Europe*, ICP/HLE 121 (1994). [www.who.int/genomics/public/eu\\_declaration1994.pdf](http://www.who.int/genomics/public/eu_declaration1994.pdf)
- WHO, *Global Strategy and Plan of Action on Public Health, Innovation and Intellectual Property*, WHA61.21 (2008). [http://apps.who.int/gb/ebwha/pdf\\_files/A61/A61\\_R21-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/A61/A61_R21-en.pdf)

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## B. Regional Instruments

- WHO, *Scaling up response the response to HIV/AIDS in the European Region of WHO*, Resolution EUR/RC52/R9 (2002). [www.euro.who.int/Governance/resolutions/2002/20021231\\_4](http://www.euro.who.int/Governance/resolutions/2002/20021231_4)

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## C. Other Statements & Declarations

- Global Treatment Access Group, *The Global AIDS Crisis: 5 Steps for Canada—A Civil Society Platform for Action* (2011). [www.aidslaw.ca/gtag](http://www.aidslaw.ca/gtag).
- Open Society Foundations, *Demand for Action on TB and HIV* (2007). [www.opensocietyfoundations.org/press-releases/public-health-watch-and-partners-demand-urgent-action-tb-and-hiv](http://www.opensocietyfoundations.org/press-releases/public-health-watch-and-partners-demand-urgent-action-tb-and-hiv). Available in French, Portuguese and Spanish.
- Open Society Foundations, *Human Rights and HIV/AIDS: Now More Than Ever* [Joint Statement] (2009). [www.hivhumanrightsnow.org](http://www.hivhumanrightsnow.org). Available in Arabic, Bulgarian, Chinese, French, German, Portuguese, Romanian, Russian, Spanish.
- *Oslo Declaration on HIV Criminalization* [international civil society organizations] (Feb. 13, 2012). [www.hivjustice.net/oslo/](http://www.hivjustice.net/oslo/).

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## D. General Resources

- Amon J. *Preventing the Further Spread of HIV/AIDS: The Essential Role of Human Rights*, Human Rights Watch (2006). [www.hrw.org/legacy/wr2k6/hivaid/hivaid.pdf](http://www.hrw.org/legacy/wr2k6/hivaid/hivaid.pdf).
- Fundación Huésped, *Guía de Buenas Prácticas ético legales en VIH/sida* (2012). [www.huesped.org.ar/wp-content/uploads/2012/07/BP-Etico-Legales-WEB.pdf](http://www.huesped.org.ar/wp-content/uploads/2012/07/BP-Etico-Legales-WEB.pdf). Available in Spanish.
- Global Commission on HIV and the Law, *HIV and the Law: Rights and Health* (July 2012). [www.hivlawcommission.org/index.php/report](http://www.hivlawcommission.org/index.php/report). Available in Spanish, French and Russian.
- Inter-Parliamentary Union, UNDP & UNAIDS, *Taking action against HIV: A handbook for parliamentarians*, No. 15 (2007). [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).
- Open Society Institute, *10 Reasons Why Human Rights Should Occupy the Centre of the Global AIDS Struggle* (2009). [www.hivhumanrightsnow.org](http://www.hivhumanrightsnow.org).
- Open Society Institute, UNAIDS, and WHO, *The Role of Human Rights in Ensuring Universal Access to HIV Testing and Counselling* (2010). [www.opensocietyfoundations.org/sites/default/files/hiv-testing-human-rights-20091012.pdf](http://www.opensocietyfoundations.org/sites/default/files/hiv-testing-human-rights-20091012.pdf).

- Robins S, “From ‘Rights’ to ‘Ritual’”: AIDS Activism in South Africa.” *American Anthropologist* 108, no 2 (2006):312-323. <http://onlinelibrary.wiley.com.ezp-prod1.hul.harvard.edu/doi/10.1525/aa.2006.108.2.312/pdf>.
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- UNAIDS and OHCHR, *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version* (2006). [http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines_en.pdf).
- UNAIDS and OHCHR, *Handbook on HIV and Human Rights for National Human Rights Institutions* (2007). [www.ohchr.org/Documents/Publications/HandbookHIVNHRIs.pdf](http://www.ohchr.org/Documents/Publications/HandbookHIVNHRIs.pdf). Available in French and Spanish.
- UNAIDS, *Terminology Guidelines* (October 2011). [www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118\\_terminology-guidelines\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf).
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- UN Human Rights Council, *Report of the UN High Commissioner on the protection of human rights in the context of HIV and AIDS*, A/HRC/19/37 (2011). [www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.37\\_en.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.37_en.pdf).
- Vasquez J, *Pan American Health organization, Human Rights & Health: Persons Living with HIV/AIDS* (2008). [www.paho.org/english/dd/pub/10069\\_HIV-Aids.pdf](http://www.paho.org/english/dd/pub/10069_HIV-Aids.pdf).

## E. Right to Non-Discrimination and Equality

- AVERT, “HIV and AIDS Stigma and Discrimination.” [www.avert.org/hiv-aids-stigma.htm#contentTable1](http://www.avert.org/hiv-aids-stigma.htm#contentTable1).
- Bor J et al, *Social exposure to an antiretroviral treatment programme in rural KwaZulu Natal*, (Africa Centre and University of Kwazulu-Natal, 2011). [www.africacentre.ac.za/Portals/0/News%20Archive/SA%20AIDS%20Conf%202011/02%20JacobBor.pdf](http://www.africacentre.ac.za/Portals/0/News%20Archive/SA%20AIDS%20Conf%202011/02%20JacobBor.pdf).
- Global Network of People Living with HIV (GNP+), *Evidence Brief: Stigma and Discrimination at Work: Findings from the People Living With HIV Stigma Index* (2012). [www.gnpplus.net/images/stories/Rights\\_and\\_stigma/SI\\_WorkBriefing\\_Online.pdf](http://www.gnpplus.net/images/stories/Rights_and_stigma/SI_WorkBriefing_Online.pdf).
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- UNAIDS, *Key Programmes to Reduce Stigma and Discrimination and Increase Access to Justice in National HIV Responses*, Guidance Note (2012). [www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key\\_Human\\_Rights\\_Programmes\\_en\\_May2012.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_May2012.pdf).
- UNAIDS, *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes: A resource for national stakeholders in the HIV response* (2007). [http://data.unaids.org/pub/Report/2008/JC1521\\_stigmatisation\\_en.pdf](http://data.unaids.org/pub/Report/2008/JC1521_stigmatisation_en.pdf).



- UNAIDS & Canadian HIV/AIDS Legal Network, *Courting rights: case studies in litigating the human rights of people living with HIV: UNAIDS Best Practice Series* (2006). [http://data.unaids.org/Publications/IRC-pub07/jc1189-courtingrights\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1189-courtingrights_en.pdf).

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## F. Right to Marry and to Found a Family

- Open Society Institute, *Mandatory Pre-Marital HIV Testing: An Overview* (2010). [www.soros.org/sites/default/files/mandatory-premarital-hiv-testing-20100513.pdf](http://www.soros.org/sites/default/files/mandatory-premarital-hiv-testing-20100513.pdf).

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## G. Right to Privacy

- Csete J and Elliott R, “Scaling up HIV testing: human rights and hidden costs,” *HIV/AIDS Policy & Law Review* 11, no. 1 (2006): 5-10. [www.aidslaw.ca/publications/publicationsdocEN.php?ref=228](http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=228). Available in French.
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- WHO and UNAIDS, *UNAIDS/WHO Policy Statement on HIV Testing* (2004). [http://data.unaids.org/unadocs/hivtestingpolicy\\_en.pdf](http://data.unaids.org/unadocs/hivtestingpolicy_en.pdf).

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## H. Freedom of Liberty of Movement

(See also Key Populations: “Refugees and Internally Displaced Persons”)

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A journal dedicated to studying the relationship between human rights and health. Three issues of the journal have focused on HIV/AIDS and human rights.
  - HIV/AIDS Policy and Law Review. [www.aidslaw.ca](http://www.aidslaw.ca).  
Provides analysis and summaries of current developments in HIV/AIDS-related policy, law, and human rights.
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- Act Up (AIDS Coalition to Unleash Power): [www.actupny.org](http://www.actupny.org).
- AIDS Law Unit of the Legal Assistance Centre (Namibia): [www.lac.org.na](http://www.lac.org.na).
- AIDS Legal Network (South Africa): [www.aln.org.za](http://www.aln.org.za).
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- AVERT: [www.avert.org/](http://www.avert.org/).
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## 6. WHAT ARE KEY TERMS RELATED TO HIV, AIDS AND HUMAN RIGHTS?

### A

#### ARV, ART

Acronyms for anti-retroviral and anti-retroviral treatment. Anti-retroviral drugs inhibit various phases of the life-cycle of the human immunodeficiency virus (HIV), thus reducing HIV-related symptoms and prolonging life-expectancy of people living with HIV. Treatment with ARVs is also used to prevent transmission of HIV from mother to child and to prevent HIV infection following exposure.

---

### D

#### DOC

Acronym for the *Declaration of Commitment on HIV/AIDS*, adopted by the United Nations General Assembly in a special session in June 2001. The DOC recognizes that “realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS” (paragraph 58).

---

### G

#### GIPA

Abbreviation for “greater involvement of people living or affected by HIV/AIDS.” The importance and benefits of involving people living with HIV or AIDS in formulating policy and delivering services has been widely recognized, first at the 1994 Paris AIDS Summit and more recently in the *Declaration of Commitment on HIV/AIDS*.

#### **Global Fund**

Abbreviation for the Global Fund to Fight AIDS, Tuberculosis, and Malaria, the central global mechanism for channeling funds between rich and poor countries to finance national responses to HIV and AIDS.

#### **Guidelines**

Abbreviation for the *International Guidelines on HIV/AIDS and Human Rights*, an authoritative set of non-binding legal and policy recommendations issued by UNAIDS and the Office of the High Commissioner for Human Rights (OHCHR) in 1998.

---

### P

#### PEPFAR

Acronym for the President’s Emergency Plan for AIDS Relief, a 5-year, US\$15 billion AIDS package authorized by U.S. President George W. Bush and enacted by the U.S. Congress in 2003 under the *U.S. Global Leadership on HIV/AIDS, Tuberculosis and Malaria Act*. PEPFAR is the largest program to combat HIV and AIDS financed by a single donor government.

**PMTCT**

Acronym for prevention of mother-to-child transmission of HIV, or transmission during pregnancy, labor and delivery, or breastfeeding. Without treatment, approximately 15-30% of babies born to mothers living with HIV will be infected during pregnancy and delivery, and a further 5-20% will become infected through breastfeeding.

**PWA, PLWA, PLWHA**

Acronyms for person living with HIV or AIDS.

**S*****Stigma and discrimination***

The United Nations has called **stigma** and **discrimination** associated with HIV and AIDS “the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact.” **Stigmatization** leads to **discrimination**.

1. **Stigma** is “a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons.” People who are stigmatized are usually considered deviant or shameful for some reason or other, and as a result are shunned, avoided, discredited, rejected, restrained or penalized. As such, stigma is an expression of social and cultural norms, shaping relationships among people according to those norms. Stigma marks the boundaries a society creates between “normals” and “outsiders,” between “us” and “them.”
2. **Discrimination** in the context of HIV and AIDS has been defined as “any measure entailing any arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health.” Discrimination can be **legitimate** and **illegitimate**.

**Illegitimate** discrimination is unjustified, disproportionate, and arbitrary. A measure or an action is *unjustified* if it lacks rational and objective reasons. It is *disproportionate* if the means employed and their consequences far exceed or do not achieve the aims pursued. It is *arbitrary* if it seriously infringes the rights of the individual and is not necessary to protect the health of others.

**U****UNAIDS**

Acronym for the Joint United Nations Programme on HIV/AIDS, a consortium of eight United Nations agencies addressing various aspects of the global AIDS epidemic. UNAIDS has a small program dedicated to address the legal, ethical, and human rights aspects of HIV and AIDS.

# CHAPTER 3



## TUBERCULOSIS AND HUMAN RIGHTS

“ Tuberculosis is a disease of poverty and inequality. ... Many of the factors that increase vulnerability to contracting [TB] or reduce access to diagnostic, prevention and treatment services are associated with people’s ability to realize their human rights. ”

— *The Global Fund to Fight AIDS, TB and Malaria*

**Health and Human Rights Resource Guide**

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# INTRODUCTION

This chapter will introduce you to key issues and resources in tuberculosis (TB) and human rights. Some of the issues in this chapter are also addressed in Chapter 2 on HIV, AIDS and human rights.

This chapter is organized into six sections that answer the following questions:

1. How is TB a human rights issue?
2. Which are the most relevant international and regional human rights standards related to TB?
3. What is a human rights-based approach to advocacy, litigation and programming?
4. What are some examples of effective human rights-based work in the area of TB?
5. How can I find additional resources about TB and human rights?
6. What are the key terms to TB and human rights?

# I. HOW IS TUBERCULOSIS (TB) A HUMAN RIGHTS ISSUE?

## What is TB?

### What does TB stand for?

TB stands for tuberculosis, an airborne infectious disease caused by the bacterium *Mycobacterium tuberculosis*. TB typically attacks the lungs (*pulmonary TB*), although it can affect other parts of the body as well (*extra-pulmonary TB*). TB is usually transmitted through the cough, sneeze, or spit of a person with active TB. When a person breathes in these air droplets, TB bacteria enter the lungs. From the lungs, the bacteria can move through the blood to other parts of the body, such as the kidney, spine and brain.<sup>1</sup>

Many healthy people exposed to TB are able to successfully fight off infection. Their immune systems destroy the bacteria, eliminating any trace of exposure.<sup>2</sup> However, other people may lack the resistance to prevent infection or disease.<sup>3</sup> Infected individuals can progress to active TB disease and experience symptoms such as cough, chest pains, weakness, weight loss, fever and night sweats.<sup>4</sup>

If left untreated, TB kills more than half of those who develop active cases.<sup>5</sup> People with HIV and other immuno-compromised states are at higher risk of developing TB infection and disease. Additionally, people with HIV and children are at higher risk for developing extra-pulmonary TB.<sup>6</sup> Accurate diagnosis combined with treatment with anti-TB medicines can greatly reduce mortality rates.<sup>7</sup> Yet while TB is preventable and curable, barriers to accessing care and maintaining health hinder TB control efforts and contribute to a global rise in drug-resistant strains of TB.

### What are latent TB and active TB?

TB develops in two stages. The first stage, known as *latent TB* or *TB infection*, occurs when a person exposed to TB bacteria becomes infected.<sup>8</sup> When the body's immune system is unable to eliminate the bacteria, it may wall them off with tiny pieces of scar tissue known as granulomas. The bacteria stay in the body but remain dormant or inactive. The individual is infected, but does not have any symptoms and is unable to spread TB.<sup>9</sup>

1 Center for Disease Control and Prevention (CDC), *Questions and Answers about Tuberculosis* (2012). [www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf](http://www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf).

2 See High Court of South Africa, *Dudley Lee v. the Minister of Correctional Services*, Case No. 1041. [www.saflii.org/za/cases/ZAWCHC/2011/13.pdf](http://www.saflii.org/za/cases/ZAWCHC/2011/13.pdf).

3 See UCLA School of Public Health, "Susceptibility Definition." [www.ph.ucla.edu/epi/bioter/anthapha\\_def\\_a.html](http://www.ph.ucla.edu/epi/bioter/anthapha_def_a.html).

4 Center for Disease Control and Prevention, *Questions and Answers about Tuberculosis* (2012). [www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf](http://www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf).

5 Tiemersma EW et al., "Natural History of Tuberculosis: Duration and Fatality of Untreated Pulmonary Tuberculosis in HIV Negative Patients: A Systematic Review," *PLoS Medicine* 6, no. 4 (2011). [www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017601](http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017601).

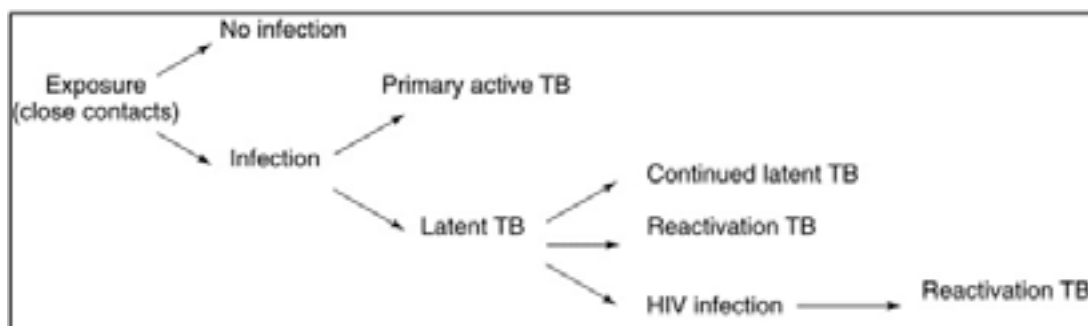
6 Zaki SA, "Extrapulmonary tuberculosis and HIV," *Lung India*, 28, no. 1, Letters to the Editor (Jan-Mar. 2011). [www.ncbi.nlm.nih.gov/pmc/articles/PMC3099522](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3099522); Walls T and Shingadia D, "Global epidemiology of paediatric tuberculosis," *Journal of Infection* 48, no. 1 (2004). [www.sciencedirect.com/science/article/pii/S016344530300121X](http://www.sciencedirect.com/science/article/pii/S016344530300121X).

7 World Health Organization (WHO), *Global Tuberculosis Control 2011* (2011). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

8 Global Health Education, "TB Tests". [www.tbfacts.org/tb-tests.html](http://www.tbfacts.org/tb-tests.html). Emphasis added.

9 Center for Disease Control and Prevention, *Tuberculosis: General Information, Fact Sheet* (2011). [www.cdc.gov/tb/publications/factsheets/general/tb.pdf](http://www.cdc.gov/tb/publications/factsheets/general/tb.pdf).

The second stage, known as active TB or TB disease, occurs when the bacteria multiply in the body, usually causing the person to become sick.<sup>10</sup> This can happen at any time, even many years after infection.<sup>11</sup> People with active TB experience symptoms which can vary depending on whether they have pulmonary or extra-pulmonary TB.<sup>12</sup> Additionally, people with TB of the lungs or throat can spread infection to others.<sup>13</sup> The following diagram, adapted from Parrish et al., helps illustrate the interaction between latent and active TB:<sup>14</sup>



## How is TB spread?

According to the World Health Organization (WHO), the probability of developing TB infection and disease increase “with malnutrition, crowding, poor air circulation, and poor sanitation—all factors associated with poverty”.<sup>15</sup> These risks are greater in crowded institutional settings such as prisons and detention centers. While TB bacteria are vulnerable to sunlight and fresh air, they can survive and circulate in closed, poorly ventilated environments. Individuals with active TB “can infect up to 10 to 15 other people through close contact over the course of a year”.<sup>16</sup> Poverty and limited access to health care fuel the spread of TB by impeding diagnosis, treatment and care. Moreover, inappropriate treatment fuels drug resistance, resulting in higher rates of TB and greater disease severity, particularly in resource-constrained settings.

## How is TB diagnosed?

There are several types of tests to determine if a person has been infected with TB. Sputum smear microscopy is one of the most widely used, particularly in high burden countries. It involves examining the sputum (lung fluid) of infected persons under a microscope to identify TB bacteria. While the test is fast and inexpensive, it tends to under-identify the number of infected persons (false negatives) and cannot test for drug resistance.

<sup>10</sup> Global Health Education, “TB Tests”. [www.tbfacts.org/tb-tests.html](http://www.tbfacts.org/tb-tests.html).

<sup>11</sup> High Court of South Africa, *Dudley Lee v. the Minister of Correctional Services*, Case No. 1041.

<sup>12</sup> Center for Disease Control and Prevention, *Questions and Answers about Tuberculosis* (2012). [www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf](http://www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf).

<sup>13</sup> Center for Disease Control and Prevention, *Tuberculosis: General Information, Fact Sheet* (Oct 2011). [www.cdc.gov/tb/publications/factsheets/general/tb.pdf](http://www.cdc.gov/tb/publications/factsheets/general/tb.pdf)

<sup>14</sup> Diagram adapted from Parrish NM, Dick JD and Bishai WR, “Mechanisms of latency in *Mycobacterium tuberculosis*”, *Trends in Microbiology* 6, no. 3 (1998): 107-112. [http://dx.doi.org/10.1016/S0966-842X\(98\)01216-5](http://dx.doi.org/10.1016/S0966-842X(98)01216-5)

<sup>15</sup> World Health Organization (WHO), *Guidelines for social mobilization. A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf)

<sup>16</sup> WHO, *Tuberculosis*, Fact sheet no. 104 (2013). [www.who.int/mediacentre/factsheets/fs104](http://www.who.int/mediacentre/factsheets/fs104).

Drug susceptibility testing (DST) is another type of testing to determine if the bacteria are susceptible to treatment or resistant to drugs. For example, culturing involves growing TB bacteria in a laboratory to confirm infection and to test for drug susceptibility.<sup>17</sup> It is currently the only method available to monitor patients' response to treatment for drug-resistant TB. However, it can take weeks and is not always available.<sup>18</sup> In 2011, 19 of the 36 countries with the high burden of TB did not have the recommended laboratory capacity to perform culture and DST.<sup>19</sup>

More sensitive diagnostic technologies have been developed in recent years. Gene Xpert MTB/RIF is a new rapid molecular test endorsed by the WHO. It can diagnose TB and drug-resistant TB within hours, and can be used at lower levels of the laboratory network than culture methods. Efforts to expand access and to decrease price are currently underway.<sup>20</sup> Nevertheless, advances in TB diagnostic capacity must also be matched by advances in capacity to provide treatment.

## What are MDR-TB and XDR-TB?

MDR-TB and XDR-TB refer to multidrug-resistant TB and extensively drug-resistant TB, respectively. Both can arise as the result of inadequate, incomplete or inconsistent treatment practices. People can also contract MDR or XDR-TB in settings where drug-resistant strains are prevalent. Treating TB requires strict adherence to a lengthy regimen of multiple drugs. Most cases of active, drug-susceptible TB can be cured with a standard six- to nine-month course of “four antimicrobial drugs that are provided with information, supervision and support to the patient by a health worker or trained volunteers.”<sup>21</sup> This approach is known as DOTS, or directly-observed therapy, short-course.

MDR-TB does not respond to standard, first-line anti-TB drugs and is difficult and costly to treat. It accounts for about 3.7% of new TB cases each year and afflicts about 500,000 people. While 60% of these cases occur in Brazil, China, India, Russia and South Africa, MDR-TB has been documented in all countries surveyed to date.<sup>22</sup> Yet in 2009, MDR-TB cases accounted for just 10% of all reported TB cases in high MDR-TB countries, and just a fraction of them were enrolled in treatment.<sup>23</sup> XDR-TB is a form of MDR-TB “that responds to even fewer available medicines, including the most effective second-line anti-TB drugs.”<sup>24</sup> XDR-TB has been identified in 84 countries, is virtually untreatable, and accounts for around 9% of all MDR-TB cases.<sup>25</sup>

Lack of diagnostic capacity has hindered effective responses to HIV-associated TB and drug-resistant TB. Few national TB programs can perform drug-susceptibility testing for first-line drugs, and even fewer have the capacity to test for second-line drug resistance. As a result, less than 5% of all MDR-TB cases are currently detected<sup>26</sup> and an even smaller percentage of XDR-TB cases are detected.<sup>27</sup> Many TB programs

17 Global Health Education, “TB Tests”. [www.tbfacts.org/tb-tests.html](http://www.tbfacts.org/tb-tests.html).

18 WHO, *Global Tuberculosis Report* (2012). [http://apps.who.int/iris/bitstream/10665/75938/1/9789241564502\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75938/1/9789241564502_eng.pdf).

19 UN General Assembly, *Report of the Special Rapporteur in the field of cultural rights: the right to enjoy the benefits of scientific progress and its applications*, A/HRC/20/26 (May 14, 2012). [www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-26\\_en.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-26_en.pdf).

20 WHO, *Global Tuberculosis Report* (2012). [http://apps.who.int/iris/bitstream/10665/75938/1/9789241564502\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75938/1/9789241564502_eng.pdf).

21 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). [www.who.int/mediacentre/factsheets/fs104](http://www.who.int/mediacentre/factsheets/fs104); WHO, “10 Facts about Tuberculosis.” [www.who.int/features/factfiles/tb\\_facts/en/index.html](http://www.who.int/features/factfiles/tb_facts/en/index.html).

22 WHO, *Multidrug-resistant tuberculosis (MDR-TB) 2013 Update* (2013). [www.who.int/tb/challenges/mdr/MDR\\_TB\\_FactSheet.pdf](http://www.who.int/tb/challenges/mdr/MDR_TB_FactSheet.pdf)

23 WHO, *Towards universal access to diagnosis and treatment of multidrug-resistant and extensively drug-resistant tuberculosis by 2015*, Progress Report (2011). [http://whqlibdoc.who.int/publications/2011/9789241501330\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789241501330_eng.pdf)

24 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). [www.who.int/mediacentre/factsheets/fs104](http://www.who.int/mediacentre/factsheets/fs104).

25 WHO, *Global Tuberculosis Control 2011* (2011). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

26 WHO, *Towards universal access to diagnosis and treatment of multidrug-resistant and extensively drug-resistant tuberculosis by 2015*, Progress Report (2011). [http://whqlibdoc.who.int/publications/2011/9789241501330\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789241501330_eng.pdf)

27 WHO “TB diagnostics and laboratory strengthening.” [www.who.int/tb/laboratory/](http://www.who.int/tb/laboratory/)

wait until the patient fails the standard drug treatment regimen before considering the possibility of drug resistance.<sup>28</sup> It is estimated under 1% of persons with MDR-TB receive the quality of care that is considered standard in high-income settings. Effective management of MDR-TB and XDR-TB requires a commitment to equity: evidence-based diagnostics, therapies and adequate health care delivery, particularly in resource-constrained settings.<sup>29</sup>

## What is the connection between TB and HIV?<sup>30</sup>

TB and HIV are overlapping epidemics which worsen health outcomes for those who are co-infected.<sup>31</sup> An estimated 14 million individuals have TB-HIV, the majority of whom live in sub-Saharan Africa. At least one third of all people with HIV are co-infected with TB, and nearly one third of all TB deaths are among people co-infected with HIV.<sup>32</sup> TB is the leading cause of death among people living with HIV worldwide—it accounts for 26% of HIV-related deaths, 99% of which occur in developing countries<sup>33</sup>

### TB and HIV health challenges

TB and HIV co-infection causes specific diagnostic and therapeutic challenges. TB and HIV exacerbate one another, accelerating the deterioration of immunological functions and resulting in premature death if untreated. Some evidence suggests that TB may exacerbate HIV infection and accelerate the progression from HIV to AIDS, although the mechanism remains unclear.<sup>34</sup> At the same time, people living with HIV are 21 to 34 times more likely to develop active TB than those without HIV, making HIV the most powerful known risk factor for progression from latent to active TB. HIV co-infection also increases the risk of TB-related death.<sup>35</sup>

There has also been research into the interaction of HIV and drug-resistant TB. At the patient level, HIV infection has not been confirmed to be an independent risk factor for the development of MDR-TB. At the population level, however, HIV has increased the absolute burden of drug-resistant TB. Regardless of whether HIV infection is an independent risk factor for drug resistance, HIV has increased the pool of immuno-compromised patients who serve as hosts and vectors for all forms of TB, including MDR-TB.<sup>36</sup>

28 WHO Expert Group Meeting, *Policy guidance on TB drug susceptibility testing (DST) and second-line drugs (SLD)* (Geneva, July 23, 2007). [http://www.who.int/tb/features\\_archive/xdr\\_mdr\\_policy\\_guidance/en/](http://www.who.int/tb/features_archive/xdr_mdr_policy_guidance/en/).

29 Dalton T et al., "Prevalence of and risk factors for resistance to second-line drugs in people with multidrug-resistant tuberculosis in eight countries: a prospective cohort study," *Lancet* 380 (2012). <http://press.thelancet.com/TB.pdf>

30 HIV stands for human immunodeficiency virus. AIDS stands for acquired immunodeficiency syndrome, which is an advanced stage of HIV defined by the demonstration of certain symptoms, infections and cancers. WHO, *HIV/AIDS: Fact Sheet No. 360*, Fact Sheet (Nov. 2012). [www.who.int/mediacentre/factsheets/fs360/en/index.html](http://www.who.int/mediacentre/factsheets/fs360/en/index.html).

31 TB Alert, "TB & HIV." <http://www.tbalert.org/index.php/about-tuberculosis/global-tb-challenges/tb-hiv>.

32 WHO, *Global Tuberculosis Control 2011* (2011): 1, 83; WHO, *TB-HIV Facts 2011-2012*. [www.who.int/tb/publications/TBHIV\\_Facts\\_for\\_2011.pdf](http://www.who.int/tb/publications/TBHIV_Facts_for_2011.pdf).

33 Pawlowski A et al., "Tuberculosis and HIV Co-Infection," *PLoS Pathogens* 8, no. 2 (2012). [www.plospathogens.org/article/info%3Adoi%2F10.1371%2Fjournal.ppat.1002464#s1](http://www.plospathogens.org/article/info%3Adoi%2F10.1371%2Fjournal.ppat.1002464#s1).

34 Ibid.

35 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241. [http://whqlibdoc.who.int/publications/2010/9789241563970\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241563970_eng.pdf).

36 Andrews JR, "Multidrug-Resistant and Extensively Drug-Resistant Tuberculosis: Implications for the HIV Epidemic and Antiretroviral Therapy Rollout in South Africa," *The Journal of Infectious Diseases* 196, suppl. 3 (2007). [http://jid.oxfordjournals.org/content/196/Supplement\\_3/S482.long](http://jid.oxfordjournals.org/content/196/Supplement_3/S482.long),



### TB and HIV programming challenges

The HIV epidemic has overwhelmed and disrupted established TB-control programs, leading to high treatment failure rates and increasing the opportunity for drug-resistant TB to emerge and spread.<sup>37</sup> Treatment for drug-resistant TB takes longer and is more complex, expensive, and toxic than treatment for drug-susceptible TB. It therefore results in lower treatment success rates and higher mortality rates, especially for those co-infected with HIV.<sup>38</sup>

Furthermore, while TB is confined to the lungs in most adult patients, it can be a systemic disease involving multiple organs in TB-HIV patients. All forms of extra-pulmonary TB, including disseminated TB, have been described in patients with HIV.<sup>39</sup> Extra-pulmonary cannot be diagnosed through microscopy, which is the most available method of diagnosis worldwide. Therefore TB is also more difficult to diagnose in persons living with HIV.<sup>40</sup> Diagnosis may also be delayed or incorrect due to logistical difficulties, such as the separation of sites for TB diagnosis and treatment from HIV diagnosis and treatment sites.

### Collaborative TB-HIV activities

TB can be cured. While there is currently no cure for HIV, people can live healthy and productive lives with antiretroviral therapy (ART).<sup>41</sup> Studies show that anti-TB drugs can prolong the lives of people with HIV by at least two years, even without ART, which can provide indefinite good health.<sup>42</sup> Early TB screening and diagnosis, preventative therapy, treatment and adherence support to people living with HIV greatly increases the manageability of both diseases. Delivering integrated services, at the same time and location, is especially critical.<sup>43</sup>

<sup>37</sup> Ibid.

<sup>38</sup> Ibid.

<sup>39</sup> Pawlowski A et al., "Tuberculosis and HIV Co-Infection," *PLoS Pathogens* 8, no. 2 (2012). [www.plospathogens.org/article/info%3Adoi%2F10.1371%2Fjournal.ppat.1002464#s1](http://www.plospathogens.org/article/info%3Adoi%2F10.1371%2Fjournal.ppat.1002464#s1).

<sup>40</sup> TB Alert, "TB & HIV." <http://www.tbalert.org/index.php/about-tuberculosis/global-tb-challenges/tb-hiv>.

<sup>41</sup> WHO, *HIV/AIDS: Fact Sheet No. 360*, Fact Sheet (Nov. 2012). [www.who.int/mediacentre/factsheets/fs360/en/index.html](http://www.who.int/mediacentre/factsheets/fs360/en/index.html).

<sup>42</sup> WHO, *Fight AIDS, fight TB, fight now: TB/HIV information pack* (2004). [www.stoptb.org/assets/documents/resources/publications/acsm/InfoPackEnglish.pdf](http://www.stoptb.org/assets/documents/resources/publications/acsm/InfoPackEnglish.pdf)

<sup>43</sup> Andrews JR et al., "Multidrug-Resistant and Extensively Drug-Resistant Tuberculosis: Implications for the HIV Epidemic and Antiretroviral Therapy Roll-out in South Africa," *Journal of Infectious Diseases* 196, Suppl. 3 (2007). [http://jid.oxfordjournals.org/content/196/Supplement\\_3/S482.long](http://jid.oxfordjournals.org/content/196/Supplement_3/S482.long),

The WHO recommends three types of collaborative TB-HIV activities: (1) establishing and strengthening mechanisms for integrated delivery of TB and HIV services; (2) reducing the burden of TB among people living with HIV and initiating early ART; and (3) reducing the burden of HIV among people with presumptive TB and diagnosed TB.<sup>44</sup> In large part to the scale-up of such activities, TB deaths in people living with HIV declined by 25% between 2004 and 2011.<sup>45</sup> Yet further progress is needed. In 2011, just 40% of TB patients were screened for HIV and just 7% of people living with HIV were screened for TB.<sup>46</sup> The combination of HIV, TB and MDR-TB in prisons has created an urgent human rights crisis in many parts of the world—in African countries such as South Africa, Uganda, and Zambia;<sup>47</sup> in Central and Eastern European countries such as Russia, Azerbaijan and Georgia;<sup>48</sup> and in Southeast Asian countries such as Cambodia, Indonesia and Thailand.<sup>49</sup> For more information on HIV, AIDS, and human rights, please see Chapter 2.

## How is TB a global epidemic?

TB is second only to HIV as the leading cause of death from an infectious disease worldwide.<sup>50</sup> Approximately 2.3 billion people—one third of the world's population—have been infected with TB, the majority of whom have latent TB and therefore do not have active symptoms and cannot transmit the disease to others.<sup>51</sup> However, around one in ten infected persons goes on to develop active TB disease. There are currently an estimated 12 million active cases of TB worldwide and nearly 9 million new cases each year.

According to the WHO, Asia and Africa carry the greatest burden of TB, with India and China accounting for nearly 40% of all cases. Africa accounts for 24% of the world's cases “and the highest rates of cases and deaths per capita”.<sup>52</sup> In 2011, 1.4 million people died from TB and over 95% of these deaths occurred in low- and middle-income countries.<sup>53</sup> While the TB death rate has dropped 40% between 1990 and 2011, the disease has never been eradicated in any country.<sup>54</sup> Experts caution that progress remains uneven across economic and social lines. These inequalities, combined with growing resistance to anti-TB drugs, require urgent attention.

44 WHO, *WHO policy on collaborative TB/HIV activities: Guidelines for national programmes and other stakeholders* (2012). [http://whqlibdoc.who.int/publications/2012/9789241503006\\_eng.pdf](http://whqlibdoc.who.int/publications/2012/9789241503006_eng.pdf)

45 Henry J. Kaiser Family Foundation, *US Global Health Policy Fact Sheet: The Global HIV/AIDS Epidemic*, Fact Sheet (Dec. 2012). [www.kff.org/hiv/aids/upload/3030-17.pdf](http://www.kff.org/hiv/aids/upload/3030-17.pdf).

46 WHO, *Tuberculosis Global Facts 2011-2012*. [www.who.int/tb/publications/2011/factsheet\\_tb\\_2011.pdf](http://www.who.int/tb/publications/2011/factsheet_tb_2011.pdf).

47 Amon J, “The HIV and TB Prison Crisis in Southern Africa,” *Huffington Post*, July 23, 2010. [www.hrw.org/news/2010/07/23/hiv-and-tb-prison-crisis-southern-africa](http://www.hrw.org/news/2010/07/23/hiv-and-tb-prison-crisis-southern-africa); Todrys K, “HIV and TB Spread Unchecked in Uganda's Prisons”, *Think Africa Press*, July 25, 2011, [www.hrw.org/news/2011/07/25/hiv-and-tb-spread-unchecked-ugandas-prisons](http://www.hrw.org/news/2011/07/25/hiv-and-tb-spread-unchecked-ugandas-prisons); Human Rights Watch, *Unjust and Unhealthy: HIV, TB, and Abuse in Zambian Prisons* (April 27, 2010). [www.hrw.org/reports/2010/04/27/unjust-and-unhealthy-o](http://www.hrw.org/reports/2010/04/27/unjust-and-unhealthy-o); Amon J, “Zambia's TB-ridden prisons”, *The Guardian*, April 27, 2010. [www.hrw.org/news/2010/04/27/zambias-tb-ridden-prisons](http://www.hrw.org/news/2010/04/27/zambias-tb-ridden-prisons); and Todrys K et al., “Imprisoned and imperiled: access to HIV and TB prevention and treatment, and denial of human rights, in Zambian prisons,” *Journal of the International AIDS Society* 14, no. 8 (2011). [www.biomedcentral.com/1758-2652/content/14/1/8/](http://www.biomedcentral.com/1758-2652/content/14/1/8/)

48 Dalton T et al., “Prevalence of and risk factors for resistance to second-line drugs in people with multidrug-resistant tuberculosis in eight countries: a prospective cohort study,” *Lancet* 380 (2012); International Committee of the Red Cross (ICRC), “Azerbaijan: combating multi-drug resistant TB in detention”, film, [www.icrc.org/eng/resources/documents/film/2013/av003a-azerbaijan-combating-mdr-tb-detention.htm](http://www.icrc.org/eng/resources/documents/film/2013/av003a-azerbaijan-combating-mdr-tb-detention.htm); and WHO, *Literature Review on Tuberculosis in Prisons* (Nov. 18, 2008). [www.who.int/tb/challenges/prisons/tb\\_in\\_prisons\\_lit\\_review\\_10febo8.pdf](http://www.who.int/tb/challenges/prisons/tb_in_prisons_lit_review_10febo8.pdf)

49 IRIN Global, “In Brief: TB, HIV warning for Cambodia's prison” (Oct 1, 2010). [www.irinnews.org/Report/90644/In-Brief-TB-HIV-warning-for-Cambodia-s-prisons](http://www.irinnews.org/Report/90644/In-Brief-TB-HIV-warning-for-Cambodia-s-prisons); IRIN Asia, “Indonesia: Overcrowding fuels TB in prisons”, Jan 25, 2010. [www.irinnews.org/Report/87852/INDONESIA-Overcrowding-fuels-TB-in-prisons](http://www.irinnews.org/Report/87852/INDONESIA-Overcrowding-fuels-TB-in-prisons); WHO, *Literature Review on Tuberculosis in Prisons* (Nov. 18, 2008). Dalton T et al., “Prevalence of and risk factors for resistance to second-line drugs in people with multidrug-resistant tuberculosis in eight countries: a prospective cohort study,” *Lancet* 380 (2012); McNeil DG, “Tuberculosis: Stubborn and Expensive to Treat, Drug-Resistant Strains Show Growth”, *The New York Times*, September 3, 2012. [www.nytimes.com/2012/09/04/science/drug-resistant-tuberculosis-strains-show-growth-worldwide.html](http://www.nytimes.com/2012/09/04/science/drug-resistant-tuberculosis-strains-show-growth-worldwide.html)

50 WHO, *Global Tuberculosis Control 2011* (2011). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

51 International Federation of Red Cross and Red Crescent Societies, *Promoting the human rights-based approach to address Tuberculosis*, (Dec. 2, 2011). [www.ifrc.org/en/news-and-media/news-stories/international/promoting-the-human-rights-based-approach-to-address-tuberculosis/](http://www.ifrc.org/en/news-and-media/news-stories/international/promoting-the-human-rights-based-approach-to-address-tuberculosis/).

52 WHO, *Global Tuberculosis Control 2011* (2011). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

53 Ibid.

54 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). [www.who.int/mediacentre/factsheets/fs104/](http://www.who.int/mediacentre/factsheets/fs104/); WHO, “10 Facts about Tuberculosis.” <http://www.who.int/features/factfiles/tuberculosis/en/>.

## How is TB a Human Rights Issue?

### Who Is Affected By TB?

Human rights are inextricably linked with who gets TB. According to the Global Fund to Fight AIDS, TB and Malaria (Global Fund):

*Tuberculosis is a disease of poverty and inequality.... Many of the factors that increase vulnerability to contracting [TB] or reduce access to diagnostic, prevention and treatment services are associated with people's ability to realize their human rights.*<sup>55</sup>

A lack of respect for human rights fuels the spread of TB<sup>56</sup> by creating conducive economic, social and environmental conditions. Key vulnerable groups include people living in poverty, ethnic minorities, women, children, people living with HIV, prisoners, homeless persons, migrants, refugees and internally displaced persons. They are more likely to be exposed to conditions that are conducive to TB development and less likely to have the information, power and resources necessary to ensure their health. Additional groups at risk include people who work in institutional settings, and people who use alcohol, tobacco and drugs.<sup>57</sup>

TB also undermines the realization of human rights by increasing vulnerability to the disease. People affected by TB suffer a double burden: the impact of the disease as well as the “consequential loss of other rights.”<sup>58</sup> TB contributes to poverty, for example, by preventing people from working and by imposing high costs related to treatment and care. People can also be subjected to arbitrary and harmful measures such as involuntary treatment, detention, isolation and incarceration. Finally, TB-associated stigma and discrimination—and overlapping discrimination based on gender, poverty, or HIV status—can affect people’s employment, housing and access to social services.

55 Global Fund to Fight AIDS, Tuberculosis and Malaria [Global Fund], *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

56 Inter-Parliamentary Union (IPU), UNAIDS, UN Development Programme (UNDP), *Taking Action Against HIV: A Handbook for Parliamentarians* (2007). [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf). Although the cited passage was written about HIV, the analysis of human rights violations apply equally to TB.

57 Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

58 Inter-Parliamentary Union, UNAIDS, UNDP, *Taking Action Against HIV: A Handbook for Parliamentarians* (2007). [www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128\\_ipu\\_handbook\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf).

These intersecting violations shape the contours of the global TB epidemic. According to the WHO, the number of people falling ill with TB each year is declining and the death rate has dropped by 40% between 1990 and 2010.<sup>59</sup> Yet this progress is offset by glaring inequalities: over 95% of all TB cases and deaths occur in developing countries and 79% of all TB-HIV cases are concentrated in Africa.<sup>60</sup> To mount an effective response to TB, public health approaches must be informed by and harmonized with the protection of civil, political, economic, social and cultural rights. Human rights are relevant to achieving universal access to quality TB prevention, diagnosis, treatment, care and support in at least three ways:

1. Human rights violations exist “as core features of risk environments, as barriers to care, and as social determinants of poor health and development”.<sup>61</sup>
2. Human rights provide a framework for holding governments and third parties responsible for developing and implementing evidence-based and rights-based responses to TB.
3. Human rights provide a framework for empowering people to reduce their vulnerability to TB and to participate in directing the policies, programs and practices that affect them.

This section examines key human rights issues that impinge on the ability of individuals and communities to maintain health, to access relevant information and services, and to avoid discriminatory and harmful measures. It also identifies interventions that can assist stakeholders in developing inclusive, equitable and effective human rights-based approaches to TB.

## How Do People Get TB?

TB is most often seen among individuals and communities who share specific biosocial risk factors for the disease, including poverty, malnutrition, crowding and HIV.<sup>62</sup> These in turn are embedded in larger economic, social and political realities known as the structural determinants of health.<sup>63</sup> TB has no natural constituencies. Instead, it clusters wherever weak and inequitable social policies create vulnerability to the disease. TB risk increases with a lack of access to education, poor nutrition, inadequate housing and sanitation, poor health services and facilities, lack of employment and social security, and political exclusion.<sup>64</sup> According to Hargreaves et al.:

*Key structural determinants of TB epidemiology include global socioeconomic inequalities, high levels of population mobility, and rapid urbanization and population growth. These conditions give rise to unequal distributions of key social determinants of TB, including food insecurity and malnutrition, poor housing and environmental conditions, and financial, geographic, and cultural barriers to health care access. In turn, the population distribution of TB reflects the distribution of these social determinants, which influence the 4 stages of TB pathogenesis: exposure to infection, progression to disease, late or inappropriate diagnosis and treatment, and poor treatment adherence and success.*<sup>65</sup>

59 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). [www.who.int/mediacentre/factsheets/fs104](http://www.who.int/mediacentre/factsheets/fs104).

60 WHO, *Global Tuberculosis Control 2011* (2011). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

61 Jurgens R et al., “People who use drugs, HIV, and human rights,” *Lancet* 376 (2010): 475-485.

62 WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

63 Lonnroth et al., “Tuberculosis: the role of risk factors and social determinants,” in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

64 Stop TB Partnership, Human Rights Task Force *Tuberculosis and Human Rights*, Working Document on TB and Human Rights (2011). [www.stoptb.org/assets/documents/global/hrtf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf](http://www.stoptb.org/assets/documents/global/hrtf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf)

65 Hargreaves et al., “The Social Determinants of Tuberculosis: From Evidence to Action,” *American Journal of Public Health* 101, no. 4 (2011): 654-662. [www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/). (emphasis added)

For example, people in urban slum housing and people in prison may share vulnerabilities in terms of poor physical space, standard of living and access to health care. Similarly, women and migrant workers may share vulnerabilities in terms of decreased economic, social and legal agency. People who use drugs and people living with HIV may share vulnerabilities in terms of stigmatized and often criminalized medical status. And finally, refugees and homeless populations may share vulnerabilities in terms of mobility and exclusion from social services. These factors in turn determine access to timely and appropriate diagnosis, treatment and care, as well as impact TB-related outcomes. According to Lonroth et al.:

*The risk of adverse health, social and financial consequences is determined by socioeconomic status, gender, social values and traditional beliefs in the community, the availability of social support services within the health care and social welfare systems, labour laws, and sick leave and pension systems.*<sup>66</sup>

The following social and structural determinants play a significant role in fuelling different stages of TB and shaping the global epidemic.

### Poor Physical Environment

Poor living and working conditions increase the risk of TB exposure and infection. Specific risk factors include more frequent contact with persons with active TB, as well as crowding and poor ventilation in homes, workplaces, health care settings, public transportation and prisons. Indeed prisons offer one of the most compelling examples of how substandard physical environments increase vulnerability to TB. Todrys and Amon describe the situation in many under-resourced prison cells in Africa:

*Overcrowding—resulting in and exacerbating food shortages, poor sanitation, and inadequate health care—contributes to the spread and development of disease. Minimal ventilation, poor isolation practices, and a significant immuno-compromised population also facilitate the transmission of TB and the development of TB disease.*<sup>67</sup>

This dangerous environment helps explain why TB is the leading cause of death among the world's prisoners, who account for 8.5% of all TB cases.<sup>68</sup> While an estimated 9 million people are incarcerated on a given day, four to six times this number pass through the prison system each year due to high prisoner turnover. Prisons act as a conduit of TB transmission, spreading the disease among prisoners, prison staff, visitors and the greater community.<sup>69</sup> As a result, prisons can have TB levels up to 100 times higher than the non-prison population, and can account for up to a third of a country's total TB burden.<sup>70</sup> The high concentration of active cases in these settings also accelerates the development of drug resistance. In some prisons up to 24% of TB cases are MDR-TB.<sup>71</sup>

66 Lonroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

67 Todrys K and Amon J, "Criminal Justice Reform as HIV and TB Prevention in African Prisons," *PLoS Medicine* 9, no. 5 (2012). [www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001215](http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001215).

68 Gegia M et al., "Developing a Human Rights-Based Program for Tuberculosis Control in Georgian Prisons," *Health and Human Rights* 13, no. 2 (2011). [www.hhrjournal.org/index.php/hhr/article/view/429/715](http://www.hhrjournal.org/index.php/hhr/article/view/429/715).

69 Amon J, "The HIV and TB Prison Crisis in Southern Africa," *Huffington Post*, July 23, 2010. [www.hrw.org/news/2010/07/23/hiv-and-tb-prison-crisis-southern-africa](http://www.hrw.org/news/2010/07/23/hiv-and-tb-prison-crisis-southern-africa).

70 WHO, "Tuberculosis in Prisons." [www.who.int/tb/challenges/prisons/en/index.html](http://www.who.int/tb/challenges/prisons/en/index.html); Gegia M et al., "Developing a Human Rights-Based Program for Tuberculosis Control in Georgian Prisons," *Health and Human Rights* 13, no. 2 (2011). <http://www.hhrjournal.org/index.php/hhr/article/view/429/678>.

71 WHO, "Tuberculosis in Prisons." [www.who.int/tb/challenges/prisons/en/index.html](http://www.who.int/tb/challenges/prisons/en/index.html).

Similar mechanisms are at work in other crowded, poorly ventilated and underserved settings, such as in urban slum housing, barracks that house men who work in mines, and refugee and internally displaced persons (IDP) camps. For example, the Office of the UN High Commissioner for Refugees (UNHCR) reports that 85% of the world's 32 million refugees and displaced persons originate from, and remain in, countries with high burdens of TB. The poor living conditions in many refugee and IDP camps can facilitate TB development, making the disease an increasingly important cause of sickness and death among these populations.<sup>72</sup>

### Poor Health Status

Poor health increases the risk of TB infection, progression to active disease and poor clinical outcomes. Coexistent conditions such as HIV, malnutrition, alcoholism, smoking-related conditions, silicosis, diabetes and cancer further weaken the immune system.<sup>73</sup> The impact of poor health status can be seen at the population level. In a recent analysis of 22 countries with 80% of the world's TB burden, experts estimated that total new cases might be reduced by eliminating the following health risks: malnutrition (34% fewer cases); indoor air pollution (26.2%); active smoking (22.7%); HIV infection (17.6%); alcohol use (13.1%) and diabetes (6.6%).<sup>74</sup>

The dynamic between TB and poor health is particularly lethal in institutional settings such as hospital wards and prison cells. For example, prisons often hold a high proportion of susceptible or immuno-compromised people, including drug-dependent individuals targeted by punitive drug laws.<sup>75</sup> This environment contributes to high risk of TB, HIV, hepatitis C and hepatitis B, endangering prisoners and the larger community. Risk factors include overcrowding, malnutrition, poor access to health care, sexual activity (including sexual violence), inability to access safe injecting equipment, and lack of access to drug treatment and opioid substitution therapy.

Even as overall TB prevalence is declining, it is rising in many parts of sub-Saharan Africa and the former Soviet Union due to the epidemic of HIV, TB and MDR-TB in prisons.<sup>76</sup> For example, Russia has the second largest prison population in the world after the United States, with 850,000 to one million prisoners.<sup>77</sup> Many are incarcerated for drug-related offenses. Overcrowding, poor nutrition and medical care, and inadequate infection control practices fuel TB in the country's many prisons and prison colonies. The Andrey Rylkov Foundation explains:

*Medical resources are limited and demands on the services are high. Although antiretroviral drugs are available, there is no HIV prevention and no formal drug treatment. When HIV treatment is available, the supply is inconsistent as is the treatment of TB and there are no second line drugs available to treat [MDR-TB].... Collaboration and integration with community health services is poor, and community hospitals are often unable to save the lives of patients who are released from prisons in poor health, only to die outside.<sup>78</sup>*

72 UN Office of the UN High Commissioner for Refugees and the World Health Organization, *Tuberculosis Care and Control in Refugee and Displaced Populations: An interagency field manual* (2007). [www.unhcr.org/4b4c986d9.html](http://www.unhcr.org/4b4c986d9.html).

73 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

74 Ibid.

75 Basu S, Stuckler D, and McKee M, "Addressing Institutional Amplifiers in the Dynamics and Control of Tuberculosis Epidemics," *American Journal of Tropical Medicine and Hygiene* 84, no. 1 (2011): 30-37. [www.ajtmh.org/content/84/1/30.full.pdf+html](http://www.ajtmh.org/content/84/1/30.full.pdf+html).

76 Jurgens R et al., "People who use drugs, HIV, and human rights," *Lancet* 376 (2010): 475-485.

77 Walmsley R, *World Prison Population List*, 8th ed, International Centre for Prison Studies. [www.prisonstudies.org/info/downloads/wppl-8th\\_41.pdf](http://www.prisonstudies.org/info/downloads/wppl-8th_41.pdf).

78 Sarang A, "Russian prisons as a source of tuberculosis", BMJ Group Blogs, April 28, 2011. <http://blogs.bmj.com/bmj/2011/04/28/anya-sarang-russian-prisons-as-a-source-of-tuberculosis>. See also Sarang A and Rhodes T, "'The last way' clinic: why tuberculosis remains an incurable disease in Russia", BMJ Group Blogs, April 12, 2011. <http://blogs.bmj.com/bmj/2012/04/12/anya-sarang-and-tim-rhodes-the-last-way-clinic-why-tuberculosis-remains-an-incurable-disease-in-russia>.



People who work in prisons, hospitals and others health care settings can also face increased risk of TB. According to the WHO, health care workers have an ethical obligation to attend to TB patients, even if it involves some degree of risk. At the same time, they are entitled to adequate protection against contracting TB. Therefore, governments and health care systems have a duty to provide the necessary goods and services to ensure a safe working environment.<sup>79</sup> The WHO's 2010 *Guidance on ethics of tuberculosis prevention, care and control (TB and Ethics Guidance)* provides further information about health care workers' rights and obligations with respect to TB.<sup>80</sup>

Beyond health care, TB is linked with other occupational exposures such as mining. Prolonged exposure to silica dust in mine shafts increases risk of lung diseases, particularly TB. According to the AIDS and Rights Alliance for Southern Africa, “[h]igh rates of HIV transmission and confined, humid, poorly ventilated working and living conditions further increase the risk of TB among mine workers.”<sup>81</sup> As miners cross borders in search of work, they spread and often bring it back to their home countries. A recent study of men with TB in Lesotho found that a quarter had worked in South African mines.<sup>82</sup>

TB and HIV infection increase vulnerability to human rights violations. People with TB often face abuse, stigma, and discrimination—manifested in “social ostracism, loss of income or livelihoods, denial of medical services or poor care within the health sector, loss of marriage and childbearing options, violence and loss of hope/depression (internalized stigma).”<sup>83</sup> Experts note that in areas of high HIV prevalence, “TB is perceived as a marker for HIV positivity; therefore, HIV-associated stigma is transferred to TB-infected individuals.”<sup>84</sup> This phenomenon is confirmed by one Kenyan man, who noted: “I have been stigmatized by friends who thought I was HIV positive. Every time they saw me take the drugs they thought I was taking [antiretroviral medicines].”<sup>85</sup>

TB thus contributes to ongoing cycles of poverty, vulnerability and poor health. Most costs related to TB arise prior to treatment: medical tests, drugs, consultation fees, transportation, and lost income. Additionally, TB diagnosis and treatment themselves can also be very expensive. Accessing care can cause people to incur debt or sell household assets,<sup>86</sup> leading to “catastrophic expenditures” which can impoverish entire families.<sup>87</sup> People with TB may lose income because they are sick or seeking care. They may lose their jobs entirely or be unable to find work due to the stigma associated with the disease. Finally, children whose caregiver loses income due to TB may be deprived of education, adequate nutrition and access to social services. For more information, see the section below on “Vulnerability among children”.<sup>88</sup>

79 WHO, *Ethical Issues in Tuberculosis prevention, care and control* (2011). [www.who.int/tb/publications/ethics\\_in\\_tb\\_factsheet\\_28jan11rev.pdf](http://www.who.int/tb/publications/ethics_in_tb_factsheet_28jan11rev.pdf).

80 WHO, *Guidance on ethics of tuberculosis prevention, care and control* (2010). [whqlibdoc.who.int/publications/2010/9789241500531\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf).

81 AIDS and Rights Alliance for Southern Africa, *The Mining Sector, Tuberculosis and Migrant Labour in Southern Africa: Policy and Programmatic Interventions for the Cross Border Control of Tuberculosis between Lesotho and South Africa, Focusing on Miners, Ex-Miners and Their Families* (July 2008). [www.tac.org.za/community/files/Mines\\_TB\\_and\\_Southern\\_Africa.pdf](http://www.tac.org.za/community/files/Mines_TB_and_Southern_Africa.pdf).

82 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). [www.hrw.org/node/86959](http://www.hrw.org/node/86959).

83 See Chapter 2.

84 Lonnroth et al., “Tuberculosis: the role of risk factors and social determinants,” in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

85 Howe E, “Timely Treatment for Drug-Resistant TB in Kenya”, Open Society Foundations, Voices, Mar. 2, 2012. <http://archive.blog.soros.org/2012/03/timely-treatment-for-drug-resistant-tb-in-kenya/>.

86 WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

87 Stop TB Partnership, “TB and Human Rights Task Force.” [www.stoptb.org/global/hrtf/](http://www.stoptb.org/global/hrtf/).

88 WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).



### Poor Access to Health Services and Systems

Poor access to health services creates gaps in TB diagnosis and treatment, contributing to higher levels of active TB cases, worse clinical outcomes and the development of drug resistance.<sup>89</sup> At an individual level, economic, social and legal factors often delay and impede contact with health care systems. Common barriers include a lack of money, difficulty arranging transportation to health facilities, lack of information about treatment options, fear of being stigmatized for seeking a diagnosis, and lack of social support in the event of sickness.<sup>90</sup> For many, maintaining employment may take precedence over maintaining health. The WHO states:

*Treatment for TB, particularly M/XDR-TB, is lengthy, complicated and expensive. Providing uninterrupted treatment and care remains a challenge for the health systems in many countries. People without access to a social safety net must often choose between following treatment to get well or working to support their families. Not completing treatment often means that people will fall ill again.*<sup>91</sup>

At a systemic level, vulnerable and at risk groups are also less likely to have access to functioning health care systems with appropriate treatment options, adequate patient referral chains, and strong mechanisms for coordinating care.<sup>92</sup> This is often the case in urban slums and in prisons, particularly in parts of Africa, Asia and the former Soviet republics. For example, one study on Georgian prisons noted a lack of coordinated TB screening, delays in diagnosis and therapy, unmanageable case loads, substandard facilities, and poor follow-up of patients.<sup>93</sup> Another Russian study on drug dependent TB-HIV patients documented treatment gaps following release from prison or transfers among TB facilities.<sup>94</sup>

Mobile and migrant populations are especially likely to experience fragmented or interrupted care, including total exclusion from social services. Affected groups include migrant workers, undocumented persons, the urban homeless, refugees and the internally displaced. According to Human Rights Watch:

*Normally, TB is easily and cheaply treated. However the prevalence of difficult to treat drug-resistant strains of TB, high incidence of co-infection with HIV, lack of cross-border mechanisms for referral and follow up care and surveillance, and the difficulty of treatment adherence while in transit, make mobile and migrant populations a serious health challenge.*<sup>95</sup>

89 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

90 Hargreaves et al., "The Social Determinants of Tuberculosis." *American Journal of Public Health* 101, no. 4 (2011): 654-662. [www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/).

91 WHO Regional Office for Europe, "Tackling tuberculosis means looking beyond the disease: experts meet to address its broader causes" (Jun. 29, 2012). <http://goo.gl/BooDy>.

92 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241. [http://whqlibdoc.who.int/publications/2010/9789241563970\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241563970_eng.pdf).

93 Gegia M et al., "Developing a Human Rights-Based Program for Tuberculosis Control in Georgian Prisons," *Health and Human Rights* 13, no. 2 (2011). [www.hhrjournal.org/index.php/hhr/article/view/429/715](http://www.hhrjournal.org/index.php/hhr/article/view/429/715).

94 Andrey Rylkov Foundation, *Delivery of Effective Tuberculosis Treatment to Drug Dependent HIV-positive Patients* (2010). <http://en.rylkov-fond.org/blog/tbr/effective-tb-treatment/>.

95 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). [www.hrw.org/node/86959](http://www.hrw.org/node/86959).

Even where there is point-of-care diagnostics or treatment (i.e., provided where people live or work), problems may persist “when HIV and TB are not treated together aggressively or, cross-border referral and follow up is too slow or insufficient, drug sensitivity is not properly detected.”<sup>96</sup> Legal insecurity, language difficulties and cultural barriers can compound these access issues, especially for people who migrate in search of work. According to Naing et al.:

*Transnational migrant workers are commonly surrounded by difficult and exploitative circumstances, which may be a result of their terms of employment and often precarious legal status.... Migration itself also has a major impact on access to and utilization of health services by migrant and host populations. There are many barriers to access health services for migrants, such as the fact that migrants need documents to be able to get healthcare services without fear.*<sup>97</sup>

In South Africa, for example, Human Rights Watch has documented cases in which migrants were denied emergency TB treatment because they lacked identity documents or were foreign. As a result, many were forced to visit multiple facilities or to go without treatment, resulting in “late diagnosis and treatment and poorer overall health in migrant communities”.<sup>98</sup>

### Unequal TB Treatment and Care

Effective TB diagnostics and therapies have been available for decades, yet many individuals continue to receive substandard care or none at all. This may be due to poverty or other marginalized status. For example, States have a duty to ensure that prisoners receive adequate health services, and that they are at least the same standard of care as those provided to the general population. The limited provision of TB services in prisons described above violates international human rights law.

Additionally, many people who use drugs face unduly restrictive conditions in accessing TB services. This is particularly problematic in Russia, where inpatient treatment is the norm and harm reduction services are denied. If patients leave TB clinics to obtain drugs, they are punished with discontinuation of TB treatment.<sup>99</sup> According to the Andrey Rylkov Foundation, the “[i]nability of the health system to offer adequate drug treatment creates an institutionalized ‘trap,’ when drug dependent patients are excluded from stable TB treatment de-facto.”<sup>100</sup>

96 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). [www.hrw.org/node/86959](http://www.hrw.org/node/86959).

97 Naing T et al., “Migrant workers’ occupation and healthcare-seeking preferences for TB-suspicious symptoms and other health problems: a survey among immigrant workers in Songkhla province, southern Thailand,” *BMC International Health and Human Rights* 12 (2012): 22. [www.biomedcentral.com/1472-698X/12/22](http://www.biomedcentral.com/1472-698X/12/22).

98 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). [www.hrw.org/node/86959](http://www.hrw.org/node/86959).

99 Andrey Rylkov Foundation, Canadian HIV/AIDS Legal Network, and Eurasian Harm Reduction Network, “*Atmospheric Pressure*”: *Russian Drug Policy as a Driver for Violations of the UN Convention against Torture*, Shadow Report to the UN Committee against Torture in relation to the review of the Fifth Periodic Report of the Russian Federation (2011). <http://en.rylkov-fond.org/wp-content/uploads/2011/12/ARF-CAT-Russia-ENG-2-Nov.pdf>.

100 Sarang A et al., *Delivery of Effective Tuberculosis Treatment to Drug Dependent HIV-positive Patients*, Andrey Rylkov Foundation (2011). <http://en.rylkov-fond.org/wp-content/uploads/2011/07/delivery-of-tb-treatment.pdf>.

Treatment disparities are also linked to global funding and policy inadequacies in resource-constrained settings.<sup>101</sup> Existing treatment standards sometimes fail to account for the flexibility required to effectively manage drug resistant TB. Global TB policy has emphasized inexpensive, standardized interventions to treat MDR-TB in low-income settings, despite the success of flexible, tailored protocols in high-income settings. As a result, less than 1% of people with newly diagnosed MDR-TB receive treatment that is considered the standard of care in the United States. Additionally, these divergent approaches to MDR-TB treatment have increased the intensity and scope of the epidemic.<sup>102</sup>

The Green Light Committee Initiative (GLC) was established to address unequal access to MDR-TB treatment and care, including access to affordable second-line drugs and scale-up of MDR-TB services.<sup>103</sup> The Global Drug Facility, established in 2001, provides TB drugs to countries that could otherwise not afford them either in the form of grants or at the lowest possible price. At the end of 2011, 20 million treatment courses were delivered to 93 countries.<sup>104</sup>

Yet due to a lack of market incentive, TB continues to receive little attention from companies that develop improved medicines. To address this neglect, The *Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines* were created to provide guidelines for pharmaceutical companies on issues including transparency, quality, clinical trials, neglected disease, patents, pricings, ethics, marketing and partnerships.<sup>105</sup> Guidelines 23-25 address the steps that pharmaceutical companies should take to address the neglect of poverty-related diseases. The right to the highest attainable standard of health requires that existing medicines are accessible as well as that much-needed new medicines are developed as soon as possible.<sup>106</sup>

### Vulnerability Among Women

TB afflicts women during their most economically active years and is among the top three causes of death among women aged 15 to 44 worldwide. In 2011, an estimated one third of the 8.7 million new TB cases were among women and 500,000 women died from TB.<sup>107</sup> TB is linked with poor reproductive health outcomes, such as risk of infertility, premature birth, obstetric morbidity, and low birth weight.<sup>108</sup> According to the WHO, vulnerability to TB is related to women's unequal social status and economic dependence:

*Women in many countries have to overcome several barriers before they can access health care. Where they undertake multiple roles in reproduction, production and child care, they may be left with less time to reach diagnostic and curative services than men.... Women may be given less priority for health needs and generally have less decision-making power over the use of household resources. They often have less knowledge of TB, especially of its signs and symptoms, than men, related to the higher rate of illiteracy among women than among men worldwide.<sup>109</sup>*

101 Keshavjee S and Beauvais SG, "No One Should Die Of Tuberculosis In The 21st Century," *Huffington Post*, Mar. 24, 2012. [www.huffingtonpost.com/sal-maan-keshavjee/world-tuberculosis-day\\_b\\_1375891.html](http://www.huffingtonpost.com/sal-maan-keshavjee/world-tuberculosis-day_b_1375891.html).

102 Keshavjee S and Farmer P, "Tuberculosis, Drug Resistance, and the History of Modern Medicine," *New England Journal of Medicine* 367, no. 10 (2012): 931-936. [www.nejm.org/doi/full/10.1056/NEJMr1205429](http://www.nejm.org/doi/full/10.1056/NEJMr1205429).

103 WHO, *Summary of the New Global Framework to support MDR-TB management scale-up*. [www.who.int/tb/challenges/mdr/greenlightcommittee/new-global-framework\\_summary.pdf](http://www.who.int/tb/challenges/mdr/greenlightcommittee/new-global-framework_summary.pdf).

104 Stop TB Partnership, "Global Drug Facility." [www.stoptb.org/gdf/](http://www.stoptb.org/gdf/).

105 UN General Assembly, *Note by the Secretary-General on The Right to Health*, A/63/263 (Aug 11, 2008). [www.who.int/medicines/areas/human\\_rights/A63\\_263.pdf](http://www.who.int/medicines/areas/human_rights/A63_263.pdf).

106 Ibid.

107 WHO, *Global Tuberculosis Control 2011* (2011). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

108 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

109 WHO, *Addressing Poverty in TB Control: Options for National TB Control Programmes* (2005). [http://whqlibdoc.who.int/hq/2005/WHO\\_HTM\\_TB\\_2005.352.pdf](http://whqlibdoc.who.int/hq/2005/WHO_HTM_TB_2005.352.pdf).

Women often wait longer to seek diagnosis and treatment for TB. This in turn can “increase the severity of their illness, decrease the success of treatment, and raise the risks that they will infect others.”<sup>110</sup> Where TB treatment is provided mostly via in-patients modes—the norm in many former Soviet countries—women may face particular difficulty adhering to treatment due to their child care responsibilities or inability to leave home for extended periods. While men and women may both face economic consequences related TB stigma, women can also face lost marriage prospects, divorce, desertion and separation from their children.<sup>111</sup>

Gender-based inequality can also impair women’s ability to exercise and claim their human rights, including the rights to information, participation, freedom of movement, privacy and individual autonomy, and health.<sup>112</sup> According to the WHO:

*Gender discrimination, even when not directly related to health care—for example denying girls and women access to education, information, and various forms of economic, social and political participation—can create increased health risk. Even if the best public health services are available, a woman has to be able to decide when and how she is going to access them, and that implies that she has to have the ability to control and make decisions about her life.*<sup>113</sup>

### Vulnerability Among Children

Children are vulnerable to TB for interrelated biological and social reasons. Each year there are approximately 500,000 new TB cases and up to 70,000 TB deaths among children. TB in children often goes undetected because their symptoms are overlooked, unrecognized as TB, or difficult to diagnose and confirm.<sup>114</sup> Key risk factors for TB in children include contact with infected persons, HIV infection, age less than five years, and severe malnutrition.<sup>115</sup> According to the WHO:

*Children are exposed to TB primarily through contact with infectious adults—with special risk in high TB-HIV settings—and will continue to be at risk for TB as long as those adults remain untreated. Curing TB and preventing its spread in the wider community is thus one important strategy to reducing children’s vulnerability to TB.*<sup>116</sup>

TB in children often rapidly and imperceptibly progresses from infection to disease.<sup>117</sup> Infants and young children are at particular risk of TB meningitis, a severe and often fatal form of TB, and HIV-infected children have an especially high risk of developing TB meningitis. While the BCG (Bacille-Calmette-Gurin) vaccine can protect infants and children against certain severe forms of TB in children, it is no longer believed to be effective in protecting against pulmonary TB.<sup>118</sup> This is particularly problematic for adolescents who are at risk of developing active pulmonary TB.<sup>119</sup>

<sup>110</sup> TB Alert, “TB and Women: TB is the single biggest killer of young women.” [www.tbalert.org/worldwide/TBAndwomen.php](http://www.tbalert.org/worldwide/TBAndwomen.php).

<sup>111</sup> Courtwright A and Turner AN, “Tuberculosis and Stigmatization: Pathways and Interventions,” *Public Health Reports* 125, Suppl 4 (2010):34-42; Somma D et al., “Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia,” *International Journal of Tuberculosis and Lung Disease* 17, no. 7 (2008): 856-866. [www.who.int/tdr/publications/documents/tb-related-stigma.pdf](http://www.who.int/tdr/publications/documents/tb-related-stigma.pdf).

<sup>112</sup> WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

<sup>113</sup> Ibid.

<sup>114</sup> WHO, “Childhood Tuberculosis.” [www.who.int/tb/challenges/children/en/index.html](http://www.who.int/tb/challenges/children/en/index.html).

<sup>115</sup> WHO, *Guidance for national tuberculosis programmes on the management of tuberculosis in children* (2006). [http://whqlibdoc.who.int/hq/2006/WHO\\_HTM\\_TB\\_2006.371\\_eng.pdf](http://whqlibdoc.who.int/hq/2006/WHO_HTM_TB_2006.371_eng.pdf).

<sup>116</sup> WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

<sup>117</sup> Swaminathan S and Rekha B, “Pediatric Tuberculosis: Global Overview and Challenges”, *Clinical Infectious Diseases* 50, no. S3 (2010): 184–S194. [http://cid.oxfordjournals.org/content/50/Supplement\\_3/S184.full.pdf+html](http://cid.oxfordjournals.org/content/50/Supplement_3/S184.full.pdf+html).

<sup>118</sup> WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

<sup>119</sup> WHO, “Childhood Tuberculosis.” [www.who.int/tb/challenges/children/en/index.html](http://www.who.int/tb/challenges/children/en/index.html).

According to the WHO, “[c]hildren with TB are often poor and live in vulnerable communities where there may be a lack of access to health care.” Moreover, children who are sick with TB may be taken out of school, depriving them of their right to education. The WHO notes:

*Already marginal households that lose income or incur debt due to TB will experience even greater poverty as budgets are cut and assets sold. If their primary care giver is ill or is preoccupied with caring for other ill family members, the child’s care and education may be neglected. If the principal family provider is ill and cannot work, children risk malnutrition, which increases susceptibility to TB and brings with it lifelong deleterious effects on both health and education.<sup>120</sup>*

These risk factors are heightened for orphaned children, street children and other vulnerable categories of youth, who are more likely to experience housing insecurity, poor nutrition, lack of access to care, and lack of access to education and information.<sup>121</sup> It is estimated that there are over 10 million children orphaned as the result of a parent dying from TB.<sup>122</sup>

### What Happens to People Affected by TB?

Current responses to TB often fail to respect the human rights of people who are vulnerable, at risk or affected by the disease. Under international human rights law, States must respect, protect, and fulfill the human rights of all people, including those with TB. The duty to *respect* means that States must refrain from interfering with the enjoyment of rights. The duty to *protect* means that States must prevent other actors from infringing on these rights. Finally, the duty to *fulfill* means that States must adopt all appropriate legislative, administrative, budgetary, judicial, and other measures toward the full realization of these rights.<sup>123</sup>

To fulfill the right to health, States must take immediate and targeted steps to ensure that health services, goods and facilities are available, accessible, acceptable and of quality. As the Global Fund notes, “[t]he right to non-discrimination, including on the grounds of social and health status, is an immediately enforceable obligation”.<sup>124</sup> Additionally, every TB patient is entitled to benefit from advanced and high-quality treatments, medicines, and diagnosis methods on an equitable and affordable basis, consistent with the right to benefit from scientific progress and its applications.<sup>125</sup> States therefore have a core obligation to ensure access to high quality TB treatment, care and support, and to reduce vulnerability by guaranteeing the underlying determinants of health.

<sup>120</sup> WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

<sup>121</sup> Stop TB Partnership, “TB and Human Rights Task Force.” [www.stoptb.org/global/hrtf/](http://www.stoptb.org/global/hrtf/).

<sup>122</sup> WHO, *Global Tuberculosis Control 2011* (2011). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

<sup>123</sup> WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

<sup>124</sup> Stop TB Partnership, “TB and Human Rights Task Force.” [www.stoptb.org/global/hrtf/](http://www.stoptb.org/global/hrtf/).

<sup>125</sup> UN General Assembly, *Report of the Special Rapporteur in the field of cultural rights: the right to enjoy the benefits of scientific progress and its applications*, A/HRC/20/26 (2012).

Nevertheless, widespread concern over TB, MDR-TB, and XDR-TB has many led governments to “routinely cite TB as an example of when it may be justified to limit patients’ rights to protect the health and safety of the public.”<sup>126</sup> International law provides qualified support. Derogation clauses in the two key international human rights treaties—the International Covenant on Civil and Political Rights (ICCPR)<sup>127</sup> and the International Covenant on Economic, Social and Cultural Rights (ICESCR)<sup>128</sup>—permit restrictions on individual rights in limited circumstances, provided that they are in accordance with the law, strictly necessary to achieve a legitimate objective, and consistent with other human rights provided for.

Accordingly, many governments have enacted rights-limiting measures in the name of TB control, such as detention of infected persons in prisons, forcible admissions into hospitals, home arrests, and travel restrictions. Yet the extent to which public health concerns may constrain individual human rights is closely circumscribed by the Siracusa Principles, a non-binding document adopted by the UN Economic and Social Council in 1984.<sup>129</sup> These principles state that restrictions on human rights must be:

- provided for and carried out in accordance with the law;
- directed toward a legitimate objective of general interest;
- strictly necessary in a democratic society to achieve the objective;
- the least intrusive and restrictive available to reach the objective;
- based on scientific evidence and neither arbitrary nor discriminatory in application; and
- of limited duration, respectful of human dignity, and subject to review.<sup>130</sup>

In practice, the Siracusa Principles do not provide governments with adequate guidance for developing measures that protect public health while respecting human rights.<sup>131</sup> Public health authorities are able to exploit ambiguous provisions in the law to oversee and compel treatment, frequently in correctional facilities. This can result in rights restrictions beyond those explicitly called for.<sup>132</sup> According to Amon et al.:

*[It is argued] that involuntary detention may legitimately be used in a limited number of cases when patients infected with drug-resistant strains of TB refuse treatment.... In practice, however, some countries have invoked sweeping rights-limiting policies that affect TB patients who have not been offered the global standard of care.... Reliance on compulsory detention, when less intrusive and less restrictive measures have proven feasible and effective, is not consistent with human rights principles.<sup>133</sup>*

The authoritative interpretations of the Human Rights Committee, which oversees state implementation of the ICCPR, provides further guidance on when human rights can be restricted in the name of public health. According to Todrys et al., the 1999 General Comment on freedom of movement “stresses the

126 Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. [www.soros.org/voices/tb-human-rights-issue](http://www.soros.org/voices/tb-human-rights-issue).

127 International Covenant on Civil and Political Rights, arts. 4, 12.

128 International Covenant on Economic, Social and Cultural Rights, art. 5.

129 Todrys KE, Howe E, Amon JJ, “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

130 UN Economic and Social Council, *Siracusa principles on the limitation and derogation provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4 (1985). [www1.umn.edu/humanrts/instr/siracusaprinciples.html](http://www1.umn.edu/humanrts/instr/siracusaprinciples.html). See also WHO, *WHO Guidance on human rights and involuntary detention for xdr-tb control* (2007). [www.who.int/tb/features\\_archive/involuntary\\_treatment/en/index.html](http://www.who.int/tb/features_archive/involuntary_treatment/en/index.html).

131 Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. [www.soros.org/voices/tb-human-rights-issue](http://www.soros.org/voices/tb-human-rights-issue).

132 Todrys KE et al., “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

133 Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. [www.hhrjournal.org/blog/perspectives/limitations-tb/](http://www.hhrjournal.org/blog/perspectives/limitations-tb/).



need for restrictions to be provided for by law, demonstrably necessary, consistent with other rights in the ICCPR, and non-discriminatory. In particular, the Committee dwells on the requirement of necessity for a proposed restriction”.<sup>134</sup>

Incarceration and other coercive TB measures unjustifiably interfere with patients’ human rights and dignity.<sup>135</sup> They also neglect more effective, rights-respecting alternatives—such as the provision of community-based DOTS, adherence support (e.g., counseling or nutritional supplements to reduce the side effects of medicine), and in-patient or out-patient treatment options.<sup>136</sup> These ambulatory and community-based models of care<sup>137</sup> have been shown to be highly successful, especially in resource-constrained settings.<sup>138</sup> Moreover, there is strong evidence that rights-limiting measures increase vulnerability to TB by subjecting individuals to conditions that favor TB infection, transmission, illness and death.<sup>139</sup> They are generally considered by human rights experts to be “unnecessary from a scientific standpoint and dangerous from a programmatic perspective”.<sup>140</sup>

As an important caveat, the implementation and enforcement of rights-restricting measures related to TB varies widely at the local level. However, as Todrys et al. note, “government authorities and local laws sometimes do not fully meet, or entirely disregard, the requirements in the Siracusa Principles that restrictions on right in the name of public health be strictly necessary and the least intrusive available to reach their objective”.<sup>141</sup> The following sections describe different laws, policies and practices which undermine the health and other human rights of people affected by TB.

### Criminalization of TB Status

Criminalization of TB patients who do not complete treatment is not an effective strategy for TB control and treatment and violates basic human rights.<sup>142</sup> Failure to complete treatment can lead to imprisonment in certain countries. Criminalization however discourages individuals with TB symptoms from seeking diagnosis and treatment for fear of imprisonment and can thereby delay diagnosis and increase the risk of transmission:<sup>143</sup>

*People are more likely to use HIV and TB services if they are confident that they will not face discrimination, their confidentiality will be respected, they will have access to appropriate information and counseling, and they will not be coerced into accepting services.*<sup>144</sup>

<sup>134</sup> Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. [www.soros.org/voices/tb-human-rights-issue](http://www.soros.org/voices/tb-human-rights-issue).

<sup>135</sup> See Todrys KE et al., “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

<sup>136</sup> Ibid.

<sup>137</sup> Ambulatory care is care delivered in clinical settings on an outpatient basis. Community-based care is care delivered primarily at patients’ homes by trained community health workers. For more information, please see the Glossary at the end of this chapter.

<sup>138</sup> Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. [www.hhrjournal.org/blog/perspectives/limitations-tb/](http://www.hhrjournal.org/blog/perspectives/limitations-tb/).

<sup>139</sup> Ibid.

<sup>140</sup> Ibid.

<sup>141</sup> See “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

<sup>142</sup> Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. [www.soros.org/voices/tb-human-rights-issue](http://www.soros.org/voices/tb-human-rights-issue).

<sup>143</sup> Francis LP and Francis JG, “Criminalizing Health-Related Behaviors Dangerous to Others? Disease Transmission, Transmission-Facilitation, and the Importance of Trust,” *Criminal Law and Philosophy* 6 (2012): 47–63.

<sup>144</sup> Open Society Foundations, Ford Foundation and UNDP, *Factsheet on Human Rights, HIV, TB and Malaria* (2011). [www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet\\_human\\_rightshivtbbandmalaria.html](http://www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet_human_rightshivtbbandmalaria.html).



Criminalization and imprisonment of TB patients increases discrimination and stigmatization and intensifies the wrong done to people who are already ill. Many individuals with TB do not complete treatment due to a lack of understanding of or education about treatment methods, lack of access to drugs, and negative side effects from treatment.<sup>145</sup>

TB legislation is often focused on punishing patients who “default” from treatment rather than access to quality and affordable medicines. In some countries, patients can be imprisoned for months without proper information, legal representation, or an opportunity to defend their actions. For example, in Kenya, a patient that was placed in jail stopped taking his medicine because he had severe negative side effects that were exacerbated by hunger caused by drought. Another patient was never told how long to stay on treatment, stopped taking his medication once he felt better, and was placed in jail as a result. Kenya’s criminalization and imprisonment mechanisms are contrary to the internationally recommended standards.<sup>146</sup> TB patients are placed in prisons with criminal offenders, often in cramped living environments and without proper nutrition. While in jail, they can easily infect other prisoners or be re-infected. There are little to no mechanisms in place to ensure that other prisoners do not contract TB from the infected individuals, re-infect individuals once they are well, or spread the disease back to their homes and communities when they are released.<sup>147</sup>

### Involuntary Treatment

The issue of involuntary treatment centers on the question: when, if ever, is it justified to compel treatment of TB patients over their objection? As a preliminary matter, the Siracusa Principles state that with respect to rights-restricting measures invoked on the grounds of public health, “[d]ue regard shall be had to the international health regulations of the World Health Organization.”<sup>148</sup> The WHO affirms that it is unethical to force TB patients to undergo treatment if they have objected to it; moreover, it is also unlikely to achieve its intended public health purpose. The WHO’s TB and Ethics Guidance states in relevant part:

*In general, TB treatment should be provided on a voluntary basis, with the patient’s informed consent and cooperation... [E]ngaging the patient in decisions about treatment shows respect, promotes autonomy, and improves the likelihood of adherence. Indeed, non-adherence is often the direct result of failure to engage the patient fully in the treatment process.<sup>149</sup>*

Contagious TB patients who refuse treatment and/or infection control measures can be isolated to prevent the spread of disease. Within isolation, if patients provide an informed refusal of treatment, their decision should be respected. The WHO states:

*Forcing these patients to undergo treatment over their objection would require a repeated invasion of bodily integrity, and could put health-care providers at risk. Moreover, as a practical matter, it would be impossible to provide effective treatment without the patient’s cooperation.<sup>150</sup>*

<sup>145</sup> KELIN Kenya, “Press Release: Should we treat TB Patients like Criminals?” (Aug. 17, 2011). <http://kelinkenya.org/tag/imprisonment-of-tb-patients/>

<sup>146</sup> Ibid.

<sup>147</sup> Ibid.

<sup>148</sup> UN Economic and Social Council, *Siracusa principles on the limitation and derogation provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4 (1985). [www1.umn.edu/humanrts/instreet/siracusaprinciples.html](http://www1.umn.edu/humanrts/instreet/siracusaprinciples.html).

<sup>149</sup> WHO, *Guidance on ethics of tuberculosis prevention, care and control* (2010). [http://www.who.int/tb/features\\_archive/ethics/en/](http://www.who.int/tb/features_archive/ethics/en/).

<sup>150</sup> Ibid.

### Involuntary Isolation<sup>151</sup>

The WHO's *TB and Ethics Guidance* states that compelled isolation (and detention) is to be viewed as a last resort measure, and limited to three “exceptional circumstances” when an individual is:

- “known to be contagious, refuses treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful”;
- “known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home”;
- “highly likely to be contagious (based on symptoms and evidence of epidemiological risk factors) but refuses to undergo assessment of his/her infectious status”.<sup>152</sup>
- The given justification is that TB patients who do not voluntarily undergo diagnosis, or who fail to adhere to treatment or infection control measures, pose serious risks to public health. The WHO further states that in rare cases where compulsory isolation is justified, measures must comply with the procedural limitations set forth in the Siracusa Principles.<sup>153</sup>

Nevertheless, compulsory isolation often violates these guidelines. First, it cannot be considered an effective “last resort”, as it comes at the expense of less-restrictive measures. Community-based treatment models have proven effective to ensure patients complete treatment, while also preventing the spread of TB, when compared to more traditional hospital-based care.<sup>154</sup> This has been demonstrated in South Africa,<sup>155</sup> which has the second highest incidence of TB cases in the world, the highest rate of MDR-TB in Africa, and the fourth highest prevalence of HIV/AIDS.<sup>156</sup> Additionally, more attention is needed to support access and adherence to treatment in the first place. For example, the severe side effects of MDR-TB drugs can pose problems: “Many adults default with their treatment, after which the TB germ develops resistance to the routine antibiotics with which we treat the condition. They then infect their children with MDR (TB).”<sup>157</sup>

Second, compulsory isolation measures are often ineffective in containing TB. South Africa requires the isolation of MDR-TB and XDR-TB patients in specialist provincial hospitals for a minimum of six months. In some cases patients are held as long as two years; in others they are released after just six months. Many TB patients are isolated in sub-standard conditions that violate their basic constitutional rights as well as South African health legislation.<sup>158</sup> According to Amon et al., because no assessment of infectiousness is ever made, these patients lack access to the drugs they need, “resulting in almost universal mortality.”<sup>159</sup> In addition, given the size of the epidemic, hospital space and cost constraints make a blanket policy of isolation impractical.<sup>160</sup>

The Open Society Foundations notes that Kenya is also investing limited anti-TB resources in building expensive isolation facilities. Despite the WHO's guidance that “reasonable social supports” be provided to isolated patients and their families, in practice this may not take place. In Kenya, South Africa and else-

<sup>151</sup> Involuntary measures are those undertaken against the individual's will. Compulsory measures are also undertaken against the individual's will and may also be required by law.

<sup>152</sup> WHO, *Guidance on ethics of tuberculosis prevention, care and control* (2010). [http://www.who.int/tb/features\\_archive/ethics/en/](http://www.who.int/tb/features_archive/ethics/en/).

<sup>153</sup> Boggio A et al., “Limitations on human rights: Are they justifiable to reduce the burden of TB in the era of MDR- and XDR-TB?” *Health and Human Rights* 10, no. 2 (2008). [www.hhrjournal.org/index.php/hhr/article/view/85/169](http://www.hhrjournal.org/index.php/hhr/article/view/85/169).

<sup>154</sup> Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. [www.soros.org/voices/tb-human-rights-issue](http://www.soros.org/voices/tb-human-rights-issue).

<sup>155</sup> Heller T et al., “Community-based treatment for multidrug-resistant tuberculosis in rural KwaZulu-Natal, South Africa,” *International Journal of Tuberculosis and Lung Disease* 14, no. 4 (2010): 420-26. [www.ncbi.nlm.nih.gov/pubmed/20202299](http://www.ncbi.nlm.nih.gov/pubmed/20202299).

<sup>156</sup> Center for Disease Control and Prevention, “Tuberculosis: DTBE in South Africa.” [www.cdc.gov/tb/topic/globaltb/Southafrica.htm](http://www.cdc.gov/tb/topic/globaltb/Southafrica.htm).

<sup>157</sup> Taylor D, “Children Bear Brunt of South Africa's Tuberculosis Epidemic”, *VOA News* (Jul. 19, 2012). [www.voanews.com/content/children-bear-brunt-of-tuberculosis-epidemic/1213097.html](http://www.voanews.com/content/children-bear-brunt-of-tuberculosis-epidemic/1213097.html).

<sup>158</sup> AIDS Law Project, *Protecting Public Health and Human Rights in the Response to TB in South Africa: State and Individual Responsibilities* (2009).

<sup>159</sup> Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. [www.hhrjournal.org/blog/perspectives/limitations-tb/](http://www.hhrjournal.org/blog/perspectives/limitations-tb/).

<sup>160</sup> AIDS Law Project, *Protecting Public Health and Human Rights in the Response to TB in South Africa: State and Individual Responsibilities* (2009).

where, TB patients who are isolated may be required to leave their jobs and their families, depriving their dependents of support and increasing their vulnerability to TB. In many cases, compulsory isolation simply “fails to protect the rights of individuals, fuels stigma and discrimination, potentially worsens health status, and is deemed unnecessary from a public health standpoint.”<sup>161</sup>

### Involuntary Detention

According to the WHO TB and Ethics Guidance, the three “exceptional circumstances” described above—which determine whether involuntary isolation is ever justified—apply equally to involuntary detention. Similarly, the five Siracusa criteria set forth the applicable safeguards for implementing involuntary detention. The justification often given is that involuntary detention is justified to protect “both the human right to health and health as a public goods,” particularly in the face of high TB, MDR-TB and XDR-TB rates.<sup>162</sup> Involuntary detention, however, has not been proven to be an effective TB treatment and prevention mechanism. It can deter sick individuals from seeking diagnosis. Additionally, it does not prevent the spread of disease: because of the delay between diagnosis and admission to a facility, widespread infection may have already occurred. Poor hygiene and living standards at confinement facilities themselves can further spread infection to healthcare workers and visitors, which in turn can spread the infection to families and communities.<sup>163</sup> Lastly, drug-resistant TB has shown to be no more infectious than drug-susceptible TB, so more extreme measures are not justified for drug-resistant, including XDR-TB, patients.

The 2007 WHO Guidance on human rights and involuntary detention for xdr-tb control states that governments should make prevention and access to accurate diagnosis and high-quality treatment high priorities. Involuntary treatment or compulsory detention may be used to prevent or treat XDR-TB cases only as a last resort, only when all voluntary measures have failed or have been insufficient, and only when all criteria of the Siracusa Principles have been met.<sup>164</sup> However, involuntary detention often does not comply with applicable human rights principles in practice. According to Sacco et al.:

*... [P]ersons with TB are detained even when they are capable of adhering to infection control regimens and to treatment.... Treatment in the community has been shown to be a more effective and less rights-violating alternative to detention of people with TB, who in any case have an absolute right to freedom from ill-treatment in confinement and to due process to challenge their confinement.*<sup>165</sup>

Additionally, while involuntary confinement in theory should only limit one right—a patient’s freedom of movement—it has the potential to and often does limit many other rights, including a patient’s right to dignity if the health facility conditions are substandard, right to work if they lose their job while involuntary confined, right to raise a family if they are forcibly separated from young children and have no alternative caregiver, and right to housing if they lose their homes as a result of confinement.

South Africa demonstrates an evolving approach to detention as a means of addressing TB. Until recently, TB patients who entered the public health system faced the risk of incarceration, whereas those who could afford private sector healthcare could be treated at home. As an outgrowth of HIV advocacy, and due in

<sup>161</sup> Open Society Foundations, Ford Foundation and UNDP, *Factsheet on Human Rights, HIV, TB and Malaria* (2011). [www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet\\_human\\_rightshivtbandmalaria.html](http://www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet_human_rightshivtbandmalaria.html).

<sup>162</sup> Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. [www.hhrjournal.org/blog/perspectives/limitations-tb/](http://www.hhrjournal.org/blog/perspectives/limitations-tb/).

<sup>163</sup> Ibid.

<sup>164</sup> WHO, *Guidance on human rights and involuntary detention for xdr-tb control* (2007). [www.who.int/tb/features\\_archive/involuntary\\_treatment/en/index.html](http://www.who.int/tb/features_archive/involuntary_treatment/en/index.html).

<sup>165</sup> Sacco S, Maleche A, and Ombati O, “Forcible Isolation of Tuberculosis Patients in Kenyan Jails,” *INTERIGHTS Bulletin* 16, no. 4 (2011): 195-200. [www.interights.org/document/198/index.html](http://www.interights.org/document/198/index.html)

part to the high co-infection of HIV and TB in South Africa, South Africa's National Strategic Plan (NSP) now includes TB in its goals and strategic objectives.<sup>166</sup> It recognizes human rights violations against TB patients and outlines strong commitments to protect their rights and to move towards community-based care.<sup>167</sup> Specifically, it calls for the development and implementation of “a national policy that permits the detention of patients with drug-resistant TB only when necessary and under conditions consistent with international good practice.”<sup>168</sup>

Given evidence of the effectiveness and scalability of community-based delivery models in resource-constrained settings, involuntary detention could rarely be considered the least restrictive means available—particularly if less restrictive means have not been applied. Moreover, involuntary detention is often applied in an arbitrary and discriminatory manner based on the ability to pay for health care. According to Amon et al., “[t]he ability to pay for health care is not a rational basis for deciding who should be deprived of liberty and who should not.”<sup>169</sup>

### Failure to Address Stigmatization and Discrimination

People with TB often face profound stigma and discrimination.<sup>170</sup> They can face social rejection by family, friends and community members, expulsion from school, reduced income and loss of employment.<sup>171</sup> A recent analysis of TB stigma literature notes:

*TB stigma has a more significant impact on women and poor or less-educated community members, which is especially concerning given that these groups are often at higher risk for health disparities. TB stigma may, therefore, worsen preexisting gender- and class-based health disparities.*<sup>172</sup>

The WHO notes that patients may go to great lengths to escape stigma and isolation, “lengths that may prolong both their own suffering and the length of time they remain infectious.”<sup>173</sup> Infected individuals may hide their TB status from their families; at the same time, families may conceal TB-related death causes from the larger community.<sup>174</sup> TB stigma has been identified as a barrier to timely TB screening, diagnosis, care-seeking and adherence to and completion of treatment:

*Individuals with TB-like symptoms may first attempt to see private physicians so as to avoid TB stigma. Because private clinics typically have longer waits for appointments, this may translate to diagnostic delay and increased financial costs for patients.*<sup>175</sup>

Once treatment has begun, TB patients may fear being identified and drop out of treatment programs. TB related stigma and discrimination make people more afraid to learn their status, disclose their status

166 UNAIDS, *UNAIDS guidance for partnerships with civil society, including people living with HIV and key population*, UNAIDS Guidance Note (2011): 8. [www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236\\_guidance\\_partnership\\_civilsociety\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236_guidance_partnership_civilsociety_en.pdf); UNAIDS, *South Africa launches its new National Strategic Plan on HIV, STIs and TB, 2012–2016* (Dec 20, 2011). [www.unaids.org/en/resources/presscentre/featurestories/2011/december/20111220sansp/](http://www.unaids.org/en/resources/presscentre/featurestories/2011/december/20111220sansp/).

167 South African Department of Health, *National Strategic Plan on HIV, STIs, and TB 2012-2016* (SANAC, 2011): 14. [www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf](http://www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf)

168 Ibid.

169 Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. [www.hhrjournal.org/blog/perspectives/limitations-tb/](http://www.hhrjournal.org/blog/perspectives/limitations-tb/).

170 TARGETS TB, “Launch of the TB Anti-Stigma Toolkit.” [http://targets.lshtm.ac.uk/tb\\_news.php](http://targets.lshtm.ac.uk/tb_news.php).

171 WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). [www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf](http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf).

172 Courtwright A and Turner AN, “Tuberculosis and Stigmatization: Pathways and Interventions,” *Public Health Reports* 125, Suppl 4 (2010):34-42

173 Stop TB Partnership, “TB and Human Rights Task Force.” [www.stoptb.org/global/hrtf/](http://www.stoptb.org/global/hrtf/).

174 Courtwright A and Turner AN, “Tuberculosis and Stigmatization: Pathways and Interventions,” *Public Health Reports* 125, Suppl 4 (2010):34-42

175 Ibid.

to others, to seek care and to adhere to treatment. This increases their vulnerability, suffering and loss of other human rights. People with TB are also more likely to suffer from discriminatory measures that perpetuate stigma and exclusion. For example, in one district in Ghana, people with TB are prohibited from selling goods in public markets or attending community events. While the right to nondiscrimination is an immediately enforceable obligation under international human rights law, in practice there are few domestic laws prohibiting discrimination on the basis of TB or suspected TB status.

Societal, institutional and legal stigmatization of TB violates the human rights of individuals with TB while also impeding larger efforts at prevention and control.<sup>176</sup> The Committee on Economic, Social and Cultural Rights notes that “[n]on-discrimination and equality are fundamental components of international human rights law” and essential to the exercise of the right to health.<sup>177</sup> State parties to the ICESCR are therefore obligated to take all appropriate measures to eliminate discrimination against people on the basis of TB status. Direct measures include reform of laws and policies that discriminate against people on the basis of TB status. An example might include legislation requiring people showing active TB symptoms to enter hospitals, where they risk exposing others and being exposed to drug resistant forms of the disease.<sup>178</sup> Indirect measures focus on the conditions and attitudes contributing to discrimination, including by private individuals and entities. Education and information play an important role: this approach has been well-documented to reduce the stigma attached to HIV and to mobilize government and community resources in efforts to combat the disease.<sup>179</sup>

## What are current interventions and practices in the area of TB?

The interventions, practices, programs and policies outlined below all strive to end the HIV epidemic and support people living with TB to live lives with dignity. Some of the interventions and practices focus on the biomedical response to TB including recommended treatments, whereas others and policies focus on vulnerable groups and human rights issue areas.

### Universal Access to Treatment as Prevention

#### Quality Assured Diagnostics

A sputum smear microscopy test is the most widely used method to detect TB. However, this test has low sensitivity, especially in HIV-positive individuals and children, and is unable to determine drug-resistance. TB can also be diagnosed with culture methods or rapid molecular tests in countries with more developed laboratory capacity.<sup>180</sup> A new rapid, fully automated test called the Xpert MTB/RIF test provides a highly accurate diagnosis that identifies the presence of TB and drug-resistant TB. The new test is not as susceptible to human error and allows people to be offered proper treatment immediately.<sup>181</sup>

#### Drug Susceptibility Testing

Drug resistant TB diagnosis depends on the slow process of bacterial culture and drug susceptibility testing. Drug resistant TB patients may be inappropriately treated during this slow diagnostic process, and

<sup>176</sup> Ibid.

<sup>177</sup> UN Committee on Economic, Social and Cultural Rights, *General Comment No. 20: Non-Discrimination in Economic, Social and Cultural Rights*, E/C.12/GC/20, Art. 2, para. 2 (July 2, 2009). [www2.ohchr.org/english/bodies/cescr/comments.htm](http://www2.ohchr.org/english/bodies/cescr/comments.htm).

<sup>178</sup> Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. [www.hhrjournal.org/blog/perspectives/limitations-tb/](http://www.hhrjournal.org/blog/perspectives/limitations-tb/).

<sup>179</sup> Open Society Foundations, Ford Foundation and UNDP, *Factsheet on Human Rights, HIV, TB and Malaria* (2011). [www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet\\_human\\_rightshivtbbandmalaria.html](http://www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet_human_rightshivtbbandmalaria.html). See also Chapter 2.

<sup>180</sup> WHO, *Tuberculosis*, Fact sheet no. 104 (2013). [http://www.who.int/tb/publications/global\\_report/2010/en/](http://www.who.int/tb/publications/global_report/2010/en/).

<sup>181</sup> WHO, *Tuberculosis: Diagnostics: Xpert MTB/RIF Test*, Fact Sheet (May 2011). [www.who.int/tb/features\\_archive/factsheet\\_xpert\\_may2011update.pdf](http://www.who.int/tb/features_archive/factsheet_xpert_may2011update.pdf).

drug-resistant strains and resistance may continue to spread during this time.<sup>182</sup> Lack of diagnostic capacity is a critical barrier to effect TB treatment.<sup>183</sup>

### TB Prevention or Prophylaxis

People with latent TB should benefit from interventions to prevent progression to active disease, including isoniazid preventive therapy.<sup>184</sup> This is true even for patients who live in resource-constrained settings.

### Adherence Support

Adherence support refers to medical, social and economic initiatives to help patients follow and benefit from TB treatment and care. According to Partners In Health, it “specifically targets TB patients who face barriers to accessing care: the elderly, pregnant women, geographically isolated patients, and patients who suffer from socio-economic problems such as poverty and alcoholism”.<sup>185</sup> Examples include providing travel vouchers or transportation to health care facilities, food packages, peer support, education and follow-up, and engaging community health workers to accompany patients as they access health care.<sup>186</sup> These initiatives help ensure continuity of care and increase patients’ chances for complete recovery.

### HIV Screening and Treatment

As part of its policy guidelines on collaborative TB-HIV activities, the WHO recommends offering routine HIV testing to patients with presumptive or diagnosed TB, as well as to their partners and family members.<sup>187</sup> As the Global Fund notes:

*Early diagnosis among people living with HIV is challenging but vital. Prevention, diagnosis and treatment of TB should be integrated or coordinated to meet the needs of patients with HIV, Hepatitis C, diabetes, those on opiate substitution therapy and other common co-morbidities. Integrating and coordinating services facilitates adherence and ensures patients are not forced to choose between needed therapies.*<sup>188</sup>

Examples of a collaborative approach include HIV counseling and testing, the use of antiretroviral therapy in TB-HIV patients and isoniazid preventative therapy to reduce TB risk among HIV patients. These measures require strong links with the HIV community.

### Harm Reduction Measures

Ensuring access to harm reduction measures is an effective approach to reducing vulnerability to TB, particularly among people who use drugs and prisoners. “Harm reduction” refers to policies, programs, and practices aimed at reducing drug-related risks and harms, rather than on reducing and punishing drug use.<sup>189</sup> Examples include needle and syringe programs, safe injection facilities, opioid substitution therapy, overdose prevention, outreach and education and decriminalization of people who use drugs. Harm reduction strategies form a part of States’ human rights obligations.<sup>190</sup> They are recommended by the

<sup>182</sup> Ibid.

<sup>183</sup> WHO, “TB diagnostics and laboratory strengthening.” [www.who.int/tb/laboratory](http://www.who.int/tb/laboratory).

<sup>184</sup> WHO, *Global Tuberculosis Report 2012* (2012): 44. [www.who.int/tb/publications/global\\_report](http://www.who.int/tb/publications/global_report).

<sup>185</sup> Partners In Health, “Pavlodar: Adopting the Accompaniment Model of TB Care” (Dec. 17, 2010). [www.pih.org/news/entry/pavlodar-adopting-the-accompaniment-model-of-tb-care/](http://www.pih.org/news/entry/pavlodar-adopting-the-accompaniment-model-of-tb-care/); Partners In Health, “Accompaniment Model Informs Global Response to Shortage of Health Workers” (April 1, 2007). [www.pih.org/blog/pih-model-for-accompaniment-informs-global-response-to-shortage-of-health-workers/](http://www.pih.org/blog/pih-model-for-accompaniment-informs-global-response-to-shortage-of-health-workers/).

<sup>186</sup> WHO, *Global Tuberculosis Control 2012* (2012): 44. [www.who.int/tb/publications/global\\_report](http://www.who.int/tb/publications/global_report).

<sup>187</sup> WHO, *WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders* (2012). [http://www.who.int/tb/publications/2012/tb\\_hiv\\_policy\\_9789241503006/en/](http://www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/).

<sup>188</sup> Global Fund to Fight AIDS, Tuberculosis and Malaria [Global Fund], *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

<sup>189</sup> Open Society Foundations, “Harm Reduction.” [www.soros.org/topics/harm-reduction](http://www.soros.org/topics/harm-reduction).

<sup>190</sup> UN General Assembly, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb. 1, 2013). [www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).



WHO in its Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users.<sup>191</sup> Specific recommendations include treatment adherence programs, continuity and communication across all health care access points, and provision of the same services to drug users as provided to the general civilian population.<sup>192</sup> For more information on harm reduction and human rights, please see Chapter 4.

### Palliative Care

Providing home-based palliative care for TB and related comorbidities is a necessary complement to effective, rights-respecting TB treatment and care.<sup>193</sup> Palliative care is “seeks to improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering” and addresses the psychosocial, legal and spiritual aspects associated with life-threatening illnesses. Palliative care measures in the context of TB include pain control, relief of TB symptoms and drug side effects, nutritional support, ongoing psychosocial support and end-of-life care. Palliative care services can promote the health and improve the lives of people with TB by implementing effective infection-control in the home and in-patient settings, intensifying case finding and referral to treatment, providing effective treatment support, among other benefits.<sup>194</sup> For more information on palliative care and human rights, please see Chapter 5.

## Models of Delivery

### Point of Care Diagnostics and Treatment

There is an overemphasis on clinical interventions for Vulnerable and at risk groups, including harmful detention and in-patient hospitalization of patients with drug resistant TB. This is despite limited evidence of the effectiveness of this approach, and ample evidence of the effectiveness of ambulatory and community-based models of service delivery. More attention is needed to providing individuals with quality treatment and care where they live and where they work. Point-of-care diagnostics and treatment are needed to reach vulnerable populations where they work, such as mines and garment factories, and where they seek care, such as maternal-child health clinics and general practitioners’ offices.<sup>195</sup>

### Community-Based Care

The WHO recommends that “community-based care should always be considered before isolation or detention is contemplated. Countries and TB programmes should put in place services and support structures to ensure that community-based care is as widely available as possible.”<sup>196</sup> Community-based care can help reach vulnerable groups by reducing the costs associated economic and social costs associated with seeking continued access to care.<sup>197</sup> Sacco et al. note that community-based care is generally the appropriate method of treatment for all forms of TB.<sup>198</sup> For example, Lesotho has provided free, community-based treatment for TB since 1991. In 2007, PIH launched Lesotho’s first MDR-TB treatment program, using paid, trained community health workers to help deliver medication, support, counseling to families, and accompaniment to hospitals for very ill patients. This program is coupled with the training of “expert patients” to act as role models, the refurbishing the national TB laboratory, and the converting a former leprosy clinic into a new

191 WHO, *WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders* (2012). [http://www.who.int/tb/publications/2012/tb\\_hiv\\_policy\\_9789241503006/en/](http://www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/).

192 WHO, *Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users: An Integrated Approach* (2008). [http://whqlibdoc.who.int/publications/2008/9789241596930\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241596930_eng.pdf)

193 WHO, *Global Tuberculosis Control 2012* (2012): 44. [www.who.int/tb/publications/global\\_report](http://www.who.int/tb/publications/global_report).

194 Hospice Palliative Care Association of South Africa, *Guidelines for Providing Palliative Care to Patients with Tuberculosis* (2011). [www.hospicepalliativecaresa.co.za/pdf/patientcare/TB\\_Guidelines\\_2011.PDF](http://www.hospicepalliativecaresa.co.za/pdf/patientcare/TB_Guidelines_2011.PDF).

195 Keshavjee S, “Let’s Learn From HIV Activists How to Achieve Zero Tuberculosis Deaths”, *Huffington Post*, Jul. 25, 2012, [www.huffingtonpost.com/sal-maan-keshavjee/tb-hiv-patients-awareness\\_b\\_1700450.html](http://www.huffingtonpost.com/sal-maan-keshavjee/tb-hiv-patients-awareness_b_1700450.html).

196 Sacco S, Maleche A, and Ombati O, “Forcible Isolation of Tuberculosis Patients in Kenyan Jails,” *INTERIGHTS Bulletin* 16, no. 4 (2011): 195-200. [www.interights.org/document/198/index.html](http://www.interights.org/document/198/index.html).

197 Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

198 Sacco S, Maleche A, and Ombati O, “Forcible Isolation of Tuberculosis Patients in Kenyan Jails,” *INTERIGHTS Bulletin* 16, no. 4 (2011): 195-200. [www.interights.org/document/198/index.html](http://www.interights.org/document/198/index.html).



MDR-TB hospital.<sup>199</sup> The effectiveness of community-based models has also been demonstrated in Latvia, Estonia, Georgia, Peru, the Philippines, Nepal, and the Russian Federation.<sup>200</sup>

## Health Literacy and Reduction of Stigma and Discrimination

Reducing the stigma and discrimination associated with TB are an essential component of reducing vulnerability to the disease. This has been widely documented as effective with respect to similarly stigmatized diseases which implicate people's human rights, including HIV. Examples of relevant efforts include education and outreach to improve health literacy about the disease and prevention and training health care workers and providers about "non-discrimination, informed consent, confidentiality and duty to treat".<sup>201</sup> Other measures include legal and policy reform to eliminate all forms of discrimination against people living with and affected by TB.

## Empowering Patients and Communities

The empowerment of the most vulnerable groups is a priority, including women and children. This requires the participation, engagement and mobilization of the entire community. The Global Fund notes that "Patients and communities play an integral role in TB treatment literacy, social support, advocacy, communication and social mobilization. TB cannot be adequately addressed without meaningfully involving those most affected in the planning and implementation of policies and programs that impact them."<sup>202</sup>

## Social Protection

### Income-Generating Activities

Interventions that reduce poverty and malnutrition among vulnerability and marginalized populations can help to reduce their high TB burden. A number of social protection interventions have been shown to improve health, education and nutrition in different settings in Latin America and South Africa. Examples include direct transfers of food or money to vulnerable households and increased access to microfinancing opportunities. Sometimes these schemes have been conditioned on behavioral requirements related to improving the success of the intervention, or directly related to improving health, such as sending children to school, participating in health literacy trainings, or accessing health care. The benefits of such activities could include improving the socioeconomic circumstances of people affected by TB and reducing financial barriers to diagnosis, treatment and care.<sup>203</sup>

### Urban Regeneration

Many of the factors which increase vulnerability to TB at both the individual and population level are associated with urbanization—substandard housing, overcrowding, economic and legal insecurity and inadequate health facilities. Urban regeneration and slum upgrading schemes could reduce vulnerability to TB by directly affecting the physical environments in which people experience disease as well as increasing living standards by ensuring access to health services, schools and employment.<sup>204</sup>

199 Partners In Health, "Pavlodar: Adopting the Accompaniment Model of TB Care" (2010). <http://www.pih.org/blog/pavlodar-adopting-the-accompaniment-model-of-tb-care>; Partners In Health, "Accompaniment Model Informs Global Response to Shortage of Health Workers" (2007). <http://www.pih.org/blog/pih-model-for-accompaniment-informs-global-response-to-shortage-of-health-workers>.

200 Amon J, Girard F, and Keshavjee S, "Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.," *Health and Human Rights* (Oct. 7, 2009) ["A reply to Boggio et al."]. [www.hhrjournal.org/blog/perspectives/limitations-tb/](http://www.hhrjournal.org/blog/perspectives/limitations-tb/).

201 Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

202 Ibid.

203 Hargreaves et al., "The Social Determinants of Tuberculosis: From Evidence to Action," *American Journal of Public Health* 101, no. 4 (2011): 654–662. [www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/).

204 Ibid.

## Legal Assistance and Advocacy

### Legal Assistance

Legal assistance can assist people affected by TB claim their economic, social, cultural, political and civil rights. Providing patients with representation can help them access care, combat discrimination and challenge measures which unjustifiably restrict their substantive and due process rights to liberty and freedom of movement. For example, recent litigation in South Africa's Constitutional Court has successfully held prison authorities accountable for failure to prevent and treat TB in prisons. This work was supported by Section 27, the former AIDS Law Project, and is a successful example of legal advocacy to promote and enforce the rights of TB patients under constitutional law and human rights principles. For more information, see below: "Example 5: Litigating for prisoners exposed to TB in South African prisons."<sup>205</sup>

### Criminal Justice Reform

Reforming the criminal justice system can be a cost-effective method of reducing TB and HIV transmission, given its role in fueling the spread of TB. Poor resourcing and management of prisons, and poor judicial and correctional processing of individuals, contribute to overcrowding and substandard conditions. According to Todrys and Amon, examples of reform include reducing arbitrary pretrial detention, large-scale prisoner releases, reforming bail guidelines, expanding community service and parole programs, increasing judges, and improving access to legal representation.<sup>206</sup> Moreover, the severity of law enforcement does not meaningfully reduce the prevalence of drug use and fuels the HIV and TB epidemics.<sup>207</sup> Criminalization deters drug users from seeking prevention and care services and pushes them into environments where the risk of infectious disease transmission and other harms are increased.<sup>208</sup> Drug policy that results in criminalization, arbitrary detention, and over-incarceration of drug users needs to be reoriented to consider its health and rights implications.

## Health Systems Strengthening

Strengthening the facilities and systems in which people access health services is an essential component of the response to TB control. As the Global Fund notes, "Poor quality of care hampers global TB control efforts. Inadequate training and supervision of health workers, inconsistent drug supplies, inadequate diagnostic tests and limited resources inhibit early detection and appropriate treatment resulting in increased transmission and poor health outcomes. By tailoring services to meet the needs of patients and communities, a human rights focus will improve service delivery, ensure that resources used match community priorities and provide evidence that can be used to mobilize additional resources."<sup>209</sup> Relevant aspects of the health care system to be strengthened include health policy and regulation, mobilization and allocation of financial and human resources, improved laboratory capacity for diagnosis and detection of drug sensitivity, management and delivery of health services, management of medicines and medical technology, and data and information management.<sup>210</sup>

<sup>205</sup> See *Lee v. Minister for Correctional Services, Constitutional Court of South Africa*, Case CCT 20/12 [2012] ZACC 30. [www.saflii.org/za/cases/ZACC/2012/30.html](http://www.saflii.org/za/cases/ZACC/2012/30.html). See also the nongovernmental organization, Section 27, [www.section27.org.za](http://www.section27.org.za).

<sup>206</sup> Todrys K and Amon J, "Criminal Justice Reform as HIV and TB Prevention in African Prisons," *PLoS Medicine* 9, no. 5 (2012). [www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001215](http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001215).

<sup>207</sup> International Center for Science in Drug Policy, *The Vienna Declaration*, [www.viennadeclaration.com](http://www.viennadeclaration.com).

<sup>208</sup> International Center for Science in Drug Policy et al., *The Vienna Declaration: Leading the way to illicit drug policies based on evidence, not ideology* (2010). [www.viennadeclaration.com/wordpress/wp-content/uploads/2010/11/The-Vienna-Declaration-Progress-thus-far.pdf](http://www.viennadeclaration.com/wordpress/wp-content/uploads/2010/11/The-Vienna-Declaration-Progress-thus-far.pdf).

<sup>209</sup> Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

<sup>210</sup> Keshavjee S et al., "Building Capacity for Multidrug-Resistant Tuberculosis Treatment: Health Systems Strengthening in Lesotho," *Innovations* 2, no. 4 (2007): 87-106. [www.mitpressjournals.org/doi/abs/10.1162/itgg.2007.2.4.87?journalCode=itgg](http://www.mitpressjournals.org/doi/abs/10.1162/itgg.2007.2.4.87?journalCode=itgg).

## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO TB?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to TB. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<p><b>UN treaty body interpretation</b></p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
<b>Human rights standards</b>	<p><b>Case law</b></p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and TB.

## Abbreviations

In the tables, we use the following abbreviations to refer to the twelve treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment ( <b>CAT</b> )	Committee against Torture ( <b>CAT Committee</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
<b>Non-discrimination and Equality</b>	Arts. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
<b>Life</b>	Art. 3	Art. 6(1)				Art. 6(1)
<b>Health</b>	Art. 25		Art. 12	Art. 12	Art. 5(e)(iv)	Art. 24
<b>Bodily Integrity</b>						
<b>Freedom of Movement</b>	Art. 13	Art. 12			Art. 5(d)(i)	
<b>Arbitrary Arrest and Detention</b>	Art. 9	Art. 9				Art. 37(b)
<b>Fair Trial</b>	Art. 8, Art. 10, Art. 11	Art. 9, Art. 14, Art. 15			Art. 5(a), Art. 6	Art. 40
<b>Persons Deprived of Liberty Treated with Humanity</b>		Art. 10.1				Art. 37
<b>Torture or Cruel, Inhuman or Degrading Treatment</b>	Art. 5	Art. 7				Art. 37(a)
<b>Privacy</b>	Art. 12	Art. 17			Art. 22	Art. 16
<b>Expression and Information</b>	Art. 19	Art. 19(2)			Art. 5(d)(viii)	Art. 12, Art. 13, Art. 17
<b>Assembly and Association</b>	Art. 20	Art. 21, Art. 22			Art. 5(d)(ix)	Art. 15
<b>Enjoy Benefits of Scientific Progress</b>	Art. 27		Art. 15			
<b>Women</b>	Art. 16, Art. 25(2)	Art. 3, Art. 23	Art. 3, Art. 10(1), Art. 10(2)	All		
<b>Children</b>	Art. 25(2)	Art. 24	Art. 10(3), Art. 12(2)(a)	Art. 5(b)		All

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

**Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
<b>Non-discrimination and Equality</b>	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
<b>Life</b>	Art. 4	Art. 2		Art. I	Art. 4
<b>Health</b>	Art. 16		Art. 11, Art. 13	Art. XI	
<b>Bodily Integrity</b>					
<b>Freedom of Movement</b>	Art. 12(1), Art. 12(2)			Art. VIII	Art. 22
<b>Arbitrary Arrest and Detention</b>	Art. 6	Art. 5		Art. XXV	Art. 7(3)
<b>Fair Trial</b>	Art. 7	Art. 6		Art. XVIII	Art. 8
<b>Persons Deprived of Liberty Treated with Humanity</b>				Art. XXV	Art. 5
<b>Torture or Cruel, Inhuman or Degrading Treatment</b>	Art. 5	Art. 3			Art. 5(2)
<b>Privacy</b>		Art. 8		Art. V	Art. 11
<b>Expression and Information</b>	Art. 9	Art. 10		Art. IV	Art. 13
<b>Assembly and Association</b>	Art. 10, Art. 11	Art. 11		Art. XXI, Art. XXII	Art 15, Art. 16
<b>Enjoy Benefits of Scientific Progress</b>				Art. XIII	
<b>Women</b>	Art. 18(3)		Art. 8	Art. VII	Art. 17
<b>Children</b>	Art. 18(3)		Art. 7, Art. 17	Art. VII	Art. 19

**Table I: TB and Rights to Non-discrimination and Equality**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Persons with TB are refused medical treatment or given a lower standard of care</li> <li>• Persons with TB are prohibited from participating in the local market</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICERD 2(1)</b> States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races.</p> <p><b>ICERD 2(2)</b> States Parties shall, when the circumstances so warrant, take, in the social, economic, cultural and other fields, special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms.</p> <p><b>ICERD 5(e)(iv)</b> States Parties undertake to prohibit and to eliminate racial discrimination in the right to public health, medical care, social security and social services.</p>	<p><b>CERD:</b> Expressing concern to <b>India</b> about “reports that members of scheduled castes and scheduled and other tribes are disproportionately affected by ... tuberculosis ... and that health care facilities are either unavailable in tribal areas or substantially worse than in non-tribal areas” and recommending that the State ensure adequate health care facilities for members of scheduled castes and scheduled and other tribes and “to increase the number of doctors and of functioning and properly equipped primary health centres and health sub-centres in tribal and rural areas.” CERD/C/IND/CO/19 (2007).</p>

### Other Interpretations

#### **WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*Overarching goals and objectives.* ...[A]ll persons with TB should be treated the same way... TB patients have the right to receive advice and treatment that meets international quality standards, be free of stigmatization and discrimination, establish and join peer support networks, and benefit from accountable representation.

*The obligation to provide access to TB Services.* TB programmes should take into account the needs of all patients, and in particular, the special needs of socially vulnerable groups for whom tailored interventions should be proactively developed.... Such groups include, but are not limited to, people living in extreme poverty, indigenous populations, refugees, asylum seekers, migrants, mine workers, prisoners, substance users (including alcohol), and homeless people. In addition, the needs of women, children, and people coinfecting with HIV warrant special consideration.

#### **Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):**

*Para. 1(j).* Undertake “effective advocacy, communication and social mobilization, avoiding stigmatization and discrimination, and spreading community awareness about policies and plans for prevention and control of tuberculosis including multidrug-resistant and extensively drug-resistant tuberculosis”. *Resolution WHA 62.15.*

#### **Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):**

*Para. 1(c).* Ensuring a comprehensive framework for management and care of M/XDR-TB is developed, including community-based care, and identifying the groups most vulnerable to, and at risk of, drug-resistant TB and its impact, including people living with HIV, prisoners, mine workers, mobile populations, drug users, alcohol dependents, the poor and other vulnerable groups; and ensuring that services to prevent and treat drug-resistant TB are targeted to their needs”.

#### **Recommendations to ensure the diagnosis and treatment of tuberculosis in undocumented migrants (Int'l Union Against Tuberculosis and Lung Disease, 2008):**

*Recommendation 1.* Health authorities and/or health staff should: a) ensure easy access to low-threshold facilities where undocumented migrants who are tuberculosis suspects can be diagnosed and treated without giving their names and without fear of being reported to the police or migration officials, b) remind health staff that they have an obligation to respect confidentiality,



## Table I (cont.)

*Recommendation 2.* Each country should ensure that undocumented migrants with tuberculosis are not deported until completion of treatment, and

*Recommendation 3.* Authorities and the non-governmental sectors should raise awareness among undocumented migrants about tuberculosis, emphasising that diagnosis and treatment should be free of charge and wholly independent of migratory status.

### **Berlin Declaration on Tuberculosis (WHO European Ministerial Forum, 2007)**

*Para. 5(2).* We will adopt the Stop TB Strategy in all its components, thereby... empowering people with TB and their communities, and removing stigma.... EUR/07/5061622/5 (2007).

### **Patients' Charter for Tuberculosis Care (World Care Council, 2006):**

*Care.* The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness.

*Dignity.* The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities. The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community.

### **Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):**

*Protection of Human Rights.* Adapting national legislation to take cognizance of HIV and AIDS and TB issues specifically discrimination and stigmatization... Sp/Assembly/ATM/2 (I) Rev.3 (2006).

*Security.* The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment.

### **Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):**

*Protection of Human Rights.* Adapting national legislation to take cognizance of HIV and AIDS and TB issues specifically discrimination and stigmatization... Sp/Assembly/ATM/2 (I) Rev.3 (2006).

## Table 2: TB and the Right to Life

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Institutionalized persons face a disproportionate risk of TB infection, disease and death</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<b>ICCPR 6(1)</b> Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.	<b>HRC:</b> Expressing concern to <b>Georgia</b> at the “the still very large number of deaths of detainees in police stations and prisons, including suicides and deaths from tuberculosis” and urging the State to “ensure that every case of death in detention is promptly investigated by an independent agency.” CCPR/CO/74/GEO (2002)

## Table 3: TB and the Right to the Highest Attainable Standard of Physical and Mental Health

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Persons with TB are denied access to quality TB treatment and care in prison</li> <li>• Persons with MRD-TB are denied tailored therapies of second-line drugs</li> <li>• Government's failing to utilize donor resources to construct isolation wards</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR:</b> Expressing concern to <b>Estonia</b> about the high rate of cases of tuberculosis and recommending that “the State party intensify its efforts to combat the spread of tuberculosis.” E/C.12/1/ADD.85 (2002).</p> <p><b>CESCR:</b> Expressing concern to <b>Moldova</b> about the “rising incidence of tuberculosis in the State party and notes with particular concern the acuteness of this problem in prisons where the infection rate is more than 40 times higher than the national average” and recommending that “the State party intensify its efforts under the National Programme on Tuberculosis Prophylaxis and Control to combat the spread of tuberculosis, including by ensuring the availability of medicines and adequate sanitary conditions in prisons.” E/C.12/1/ADD.91 (2003).</p> <p><b>CESCR:</b> Expressing concern to <b>Kyrgyzstan</b> that new health threats such as the “reemergence of communicable and vaccine-preventable diseases such as tuberculosis” and urging “the State party to continue its efforts to address the prevailing health threats, and to target progressively resources to health services.” E/C.12/1/ADD.49 (2000).</p> <p><b>CESCR:</b> Expressing concern to <b>Russian Federation</b> “about the spread of drug addiction, including by way of injection, which is the main factor for the growing epidemic of HIV/AIDS, hepatitis C and tuberculosis in the Russian Federation” and urging “the State party to apply a human rights-based approach to drug users so that they do not forfeit their basic right to health.” E/C.12/RUS/CO/5 (CESCR, 2011).</p> <p><b>CESCR:</b> Expressing concern to <b>Russian Federation</b> about “the high incidence of tuberculosis in the State party, particularly in prisons, in the Republic of Chechnya and in the regions of the Far North, in particular among indigenous communities” and recommending that “the State party intensify its efforts to combat tuberculosis, under the special federal programme ‘Urgent measures to tackle tuberculosis in Russia for the period 1998-2004’, including by ensuring the availability of medicines and adequate sanitary conditions in prisons, and by taking special measures to combat the epidemic in the worst affected regions.” E/C.12/1/Add.94 (2003).</p>

Table 3 (cont.)

Human Rights Standards	Treaty Body Interpretation
<p><b>12(2)</b> The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases.</p>	<p><b>CESCR:</b> Expressing concern to the <b>Ukraine</b> that “information from the State party that in 2006, 70 persons out of 100,000 (80 out of 100,000 in rural areas) were suffering from tuberculosis, which has become the leading cause of death among persons with HIV/AIDS and is particularly prevalent among the prison population” and recommending that “the State party take urgent measures to improve tuberculosis prevention and accessibility of specialized tuberculosis treatment and medication, in particular in prisons, detention centres and police stations, and reduce delays in screening detainees for tuberculosis.” E/C.12/UKR/CO/5 (CESCR, 2008).</p> <p><b>CESCR:</b> Expressing concern to <b>Azerbaijan</b> “about overcrowding and sub-standard conditions in prisons in Azerbaijan which have given rise to a disproportionately high rate of tuberculosis and other health problems among prisoners” and recommending “that the State party continue to take measures to improve the sanitary and hygienic conditions in prisons and to ensure that the right to mental and physical health of all prisoners in Azerbaijan is respected.” E/C.12/1/Add.104 (2004).</p> <p><b>CESCR:</b> Expressing concern to <b>India</b> at the “high incidences of tuberculosis” and recommending that “the State party significantly increase its health-care expenditure, giving the highest priority to ... treating serious communicable diseases, including HIV/AIDS.” E/C.12/IND/CO/5 (2008).</p> <p><b>CESCR:</b> Expressing concern to <b>India</b> about the “overcrowding and sub-standard conditions in prisons which are operating at 200-300 per cent of their maximum capacity, which have given rise to a disproportionately high rate of tuberculosis and other health problems affecting the prisoners” and recommending that “the State party strengthen its measures to improve the sanitary and hygienic conditions in prisons and to ensure that the right to mental and physical health of all prisoners is respected” E/C.12/IND/CO/5 (2008).</p> <p><b>CESCR:</b> Expressing concern to <b>Uzbekistan</b> “about the absence of adequate health care and the poor hygienic conditions in prisons that lead to frequent tuberculosis infections of detainees” and recommending that the “State party to take measures to improve the hygienic conditions in prisons and to ensure that the right to health of all detainees in the State party is respected” E/C.12/UZB/CO/1 (2006).</p>
<p><b>CRC 24(1)</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p><b>CRC: Expressing</b> concern that malaria and TB were re-emerging in <b>Malaysia</b> and recommended that the government “[p]revent and reduce the spread of tuberculosis and malaria.” CRC/C/MYS/CO/1 (2007).</p> <p><b>CRC: Expressing</b> concern in <b>Latvia</b> at increasing rates of TB and recommended that the government “[offer] HIV-related care and treatment... including for the prevention and treatment of health problems related to HIV/AIDS, such as tuberculosis and opportunistic infections.” CRC/C/LVA/CO/2 (2006).</p> <p><b>CRC:</b> Recommending that <b>Turkmenistan</b> “[a]ddress the issue of underreporting of communicable and infectious diseases, particularly HIV/AIDS and tuberculosis.” CRC/C/TKM/CO/1 (2006).</p> <p><b>CRC:</b> Recommending that <b>Lithuania</b> “[strengthen] its efforts to implement the National Tuberculosis Prevention and Control Programme for 2003–2006.” CRC/C/LTU/CO/2 (2006).</p> <p><b>CRC:</b> Expressing concern in <b>Russia</b> “that the number of tuberculosis cases remains high” and recommending that the government “continue efforts to reduce morbidity due to tuberculosis.” CRC/C/RUS/CO/3 23 (2005).</p> <p><b>CRC:</b> Recommending that the <b>Central African Republic</b> “strengthen its efforts to combat HIV/AIDS infection, including through efforts to combat tuberculosis.” CRC/C/15/Add.138 (2000).</p>

## Table 3 (cont.)

### Other Interpretations

**Policy on Collaborative TB/HIV activities: Guidelines for national programmes and other stakeholders (WHO, 2012).** Extensive discussion of TB prevention, treatment and care options.

**WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011):**

*Recommendation 6.* Patients with MDR-TB should be treated using mainly ambulatory care rather than models of care based principally on hospitalization....

**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*The obligation to provide access to TB Services.* Governments' ethical obligation to provide universal access to TB care is grounded in their duty to fulfil the human right to health.... The obligation to provide universal access to TB care implies a duty to ensure the quality of that care.

All aspects of TB care should be provided free of charge.... It is also important to remove non-TB-specific financial barriers to accessing the health-care system, such as user fees that prevent poor people from receiving health-care services, or charges imposed on TB patients for the care of related conditions (e.g. HIV)....

As WHO has recognized, "community-based care provided by trained lay and community health workers can achieve comparable results [to hospitalization] and, in theory, may result in decreased nosocomial spread of the disease". In addition, community-based care reduces burdens on health-care facilities and is more cost effective than facility-based treatment, thereby enabling governments with limited resources to serve the greatest proportion of those in need.

**Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):**

*Para. 1.* Achieve "universal access to diagnosis and treatment of multidrug-resistant and extensively drug-resistant tuberculosis as part of the transition to universal health coverage".

*Para. 1(a).* Develop "a comprehensive framework for management and care of [MDR- and XDR-TB] that includes directly-observed treatment, community-based and patient-centred care, and which identifies and addresses the needs of persons living with HIV, the poor and other vulnerable groups, such as prisoners, mineworkers, migrants, drug users, and those dependent on alcohol, as well as the underlying social determinants of tuberculosis".

*Para. 1(b).* Strengthen "health information and surveillance systems to ensure detection and monitoring of the epidemiological profile of [MDR- and XDR-TB] and monitor achievement in its prevention and control".

*Para. 1(d).* Make "available sufficiently trained and motivated staff in order to enable diagnosis, treatment and care of tuberculosis".

*Para. 1(e).* Strengthen "laboratory systems, through increasing capacity and adequate human resources, and accelerating access to faster and quality-assured diagnostic tests".

*Para. 1(f).* Engage "all relevant public and private health-care providers in managing tuberculosis... and tuberculosis-HIV coinfection according to national policies, and strengthening primary health care in early detection, effective treatment and support to patients".

*Para. 1(g).* Ensure "that national airborne infection-control policies are developed... and implemented in every health-care facility and other high-risk settings...".

*Para. 1(h).* Ensure "an uninterrupted supply of first- and second-line medicines for tuberculosis treatment... and that quality-assured fixed-dose combination medicines of proven bioavailability are prioritized within a system that promotes treatment adherence".

*Para. 1(i).* Strengthen "mechanisms to ensure that tuberculosis medicines are sold on prescription only and that they are prescribed and dispensed by accredited public and private providers".

*Para. 1(k).* Establish "national targets in order to accelerate access to treatment, according to WHO guidelines, for [MDR- and XDR-TB] patients". *Resolution WHA 62.15.*

## Table 3 (cont.)

### **Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):**

*Para. 1(l).* Identifying and addressing the underlying social determinants of TB and M/XDR-TB. This needs action both within and outside the health system, and should be linked to broader national initiatives to ensure “health in all policies”.

*Para. 1(b).* Ensuring the removal of financial barriers to allow all TB patients equitable access to TB care, that their rights are protected, and that they are treated with respect and dignity.

### **WHO Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users (WHO, 2008):**

*Recommendation 10.* All services dealing with drug users should collaborate locally with key partners to ensure universal access to comprehensive TB and HIV prevention, treatment and care as well as drug treatment services for drug users in a holistic person-centred way that maximizes access and adherence: in one setting, if possible.

**SR Health (2006):** Commenting that the “socio-economic consequences of stigmatization and discrimination can have devastating consequences” for marginalized individuals in **Uganda**: “stigma related to tuberculosis can be greater for women: it may lead, inter alia, to ostracism, rejection and abandonment by family and friends, as well as loss of social and economic support” and recommending that all relevant actors “urgently consider whether or not the national and international programmes in relation to HIV/AIDS, tuberculosis and malaria could also enhance interventions for other diseases”. E/CN.4/2006/48/Add.2 (2006)

### **Patients’ Charter for Tuberculosis Care (World Care Council, 2006):**

*Care.* The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness. The right to receive medical advice and treatment... centering on patient needs, including those with multidrug-resistant tuberculosis (MDR-TB) or tuberculosis-human immunodeficiency virus (HIV) coinfections and preventative treatment for young children and others considered to be at high risk. The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

*Security.* The right to nutritional security or food supplements if needed to meet treatment requirements.

### **International Standards for Tuberculosis Care (Tuberculosis Coalition for Technical Assistance, 2006):**

*Standard 9.* To foster and assess adherence, a patient-centered approach to administration of drug treatment, based on the patient’s needs and mutual respect between the patient and the provider, should be developed for all patients. Supervision and support should be gender-sensitive and age-specific and should draw on the full range of recommended interventions and available support services, including patient counseling and education.

### **Political Declaration on HIV/AIDS (UN General Assembly, 2006):**

*Para. 33.* Emphasize the need for accelerated scale-up of collaborative activities on tuberculosis and HIV, in line with the Global Plan to Stop TB 2006–2015, and for investment in new drugs, diagnostics and vaccines that are appropriate for people with TB-HIV co-infection.

*Para. 34.* Commit ourselves to expanding...our capacity to deliver comprehensive HIV/AIDS programmes in ways that strengthen existing national health and social systems, including by integrating HIV/AIDS intervention into [programmes for tuberculosis].

### **Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):**

*Protection of Human Rights.* To continue promoting an enabling policy, legal and social environment that promotes human rights particularly for women, youth and children and ensure the protection of people infected and affected by HIV and AIDS, TB and Malaria and to reduce vulnerability and marginalization including conflict-affected and displaced persons, refugees and returnees.

*Access to Affordable Medicines and Technologies.* To... ensure the availability of medicines and commodities at affordable prices as well as technologies for the treatment, care and prevention of HIV and AIDS, TB and malaria including vaccines, medicines and Anti-retrovirus Therapy (ART). Sp/Assembly/ATM/2 (I) Rev.3 (2006).

### **Cairo Programme of Action of the United Nations International Conference on Population and Development (UN, 1994):**

*HIV/AIDS. 8.31.* The links between the prevention of HIV infection and the prevention and treatment of tuberculosis should be assured.

## Table 4: TB and the Right to Bodily Integrity

### Examples of Human Rights Violations

- A patient is involuntarily hospitalized for treatment even though it has not been shown that she has failed to adhere to her treatment regimen.

**Note:** The right to bodily integrity is not specifically recognized under the ICCPR or ICESCR, but has been interpreted to be part of the right to security of the person, to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health.

Similarly, the right to bodily integrity is not specifically recognized in CEDAW, although CEDAW has been widely interpreted to include the right to protection from violence against women. (See concluding observations to Thailand, CEDAW/C/1999/I/L.1/Add.6 (1999) stating that “sexual harassment, rape, domestic violence and marital rape, whether in the family, the community or the workplace, constitute violations of women’s right to personal security and bodily integrity.”)

### Other Interpretations

#### WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

*Overarching goals and objectives.* Autonomy can be defined in many ways, but is generally seen as guaranteeing individuals the right to make decisions about their own lives, including health care.... For example, respecting autonomy means that patients generally should have the right to choose among treatment options.

*Information, counselling and the role of consent.* There are several reasons to ensure that individuals undergoing TB testing and treatment receive complete and accurate information about the risks, benefits, and alternatives available to them. First, at the most basic level, people have a right to know what is being done to their bodies, and why it is being done.

*Supporting adherence to TB treatment.* Directly observed therapy should be seen as a process for providing support, motivation, and understanding to patients. It is a necessary part of TB care, but is not intended to be a method for “forcing” patients to do something against their will.... In rare instances, if all reasonable efforts to promote adherence have failed and the patient still remains infectious, involuntary isolation or detention may be considered.

*Involuntary isolation and detention as last-resort measures.* While contagious TB patients who do not adhere to treatment or who are unable or unwilling to comply with infection control measures pose significant risks to the public, those risks can be addressed by isolating the patient. Patients who are isolated should be offered the opportunity to receive treatment, but if they do not accept, their informed refusal should be respected, as the isolated patient no longer presents a public health risk. Forcing these patients to undergo treatment over their objection would require a repeated invasion of bodily integrity.

#### Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):

*Para. 1(b).* Ensuring the removal of financial barriers to allow all TB patients equitable access to TB care, that their rights are protected, and that they are treated with respect and dignity.

#### Patients’ Charter for Tuberculosis Care (World Care Council, 2006):

*Dignity.* The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities. The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community.

*Choice.* The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease. The right to choose whether or not to take part in research programs without compromising care.

**Table 5: TB and Freedom of Movement**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• TB patients under quarantine or isolation or in detention are unable to freely move or reside in a country, or to leave and return.</li> <li>• People exercising freedom of movement for work are denied TB services because they lack identity documents.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 12(1)</b> Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence.</p> <p><b>12 (2)</b> Everyone shall be free to leave any country, including his own.</p> <p><b>12 (4)</b> No one shall be arbitrarily deprived of the right to enter his own country.</p>	None.

### Other Interpretations

#### WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011):

*Recommendation 6.* Patients with MDR-TB should be treated using mainly ambulatory care rather than models of care based principally on hospitalization ...

#### WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

*Involuntary isolation and detention as last-resort measures.* Isolation or detention should be limited to exceptional circumstances... Isolation or detention should never be implemented as a form of punishment. Patients who decline treatment and who pose a risk to others should be made aware in advance that their continued refusal may result in compulsory isolation or detention....

If, in a rare individual case, a judgement is made that involuntary isolation or detention is the only reasonable means of safeguarding the public, it is essential to ensure that the manner in which isolation or detention is implemented complies with applicable ethical and human rights principles. As set forth in the Siracusa Principles, this means that such measures must be:

- *in accordance with the law;*
- *based on a legitimate objective;*
- *strictly necessary in a democratic society;*
- *the least restrictive and intrusive means available; and*
- *not arbitrary, unreasonable, or discriminatory....*

In order to make sure that these principles are followed, countries should review their public health laws to ensure that they carefully limit the scope of government authority and provide due process protections for individuals whose liberty may be restricted. In addition, in order to minimize the danger of arbitrary enforcement, countries and TB programmes should develop clear criteria and procedures for the use of non-voluntary measures, with involvement from TB patients and civil society.

#### Recommendations to ensure the diagnosis and treatment of tuberculosis in undocumented migrants (Int'l Union Against Tuberculosis and Lung Disease, 2008):

*Recommendation 1.* Health authorities and/or health staff should: a) ensure easy access to low-threshold facilities where undocumented migrants who are tuberculosis suspects can be diagnosed and treated without giving their names and without fear of being reported to the police or migration officials, b) remind health staff that they have an obligation to respect confidentiality,

*Recommendation 2.* Each country should ensure that undocumented migrants with tuberculosis are not deported until completion of treatment, and

*Recommendation 3.* Authorities and the non-governmental sectors should raise awareness among undocumented migrants about tuberculosis, emphasising that diagnosis and treatment should be free of charge and wholly independent of migratory status.



## Table 5 (cont.)

### WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):

In this regard, if a patient wilfully refuses treatment and, as a result, is a danger to the public, the serious threat posed by XDR-TB means that limiting that individual's human rights may be necessary to protect the wider public. Therefore, interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. *This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.* A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal.

### General Comment No. 27: Freedom of movement (Art.12) (UN Human Rights Committee, 1999):

*Para. 16.* States have often failed to show that the application of their laws restricting the rights enshrined in [ICCPR article 12] are in conformity with all requirements referred to... The application of restrictions in any individual case must be based on clear legal grounds and meet the test of necessity and the requirements of proportionality.

*Para. 18.* The application of the restrictions permissible under article 12, paragraph 3, needs to be consistent with the other rights guaranteed in the Covenant and with the fundamental principles of equality and non-discrimination. Thus, it would be a clear violation of the Covenant if [these rights] were restricted by making distinctions of any kind, such as on the basis of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. CCPR/C/21/Rev.1/Add.9 (1999).

### Siracusa Principles (UN Economic and Social Rights Council, 1985):

*Article 25.* Public health may be invoked as a ground for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.

*Article 26.* Due regard shall be had to the international health regulations of the World Health Organization.

*Article 39.* A state party may take measures derogating from its obligations under [ICCPR Art. 4] only when faced with a situation of exceptional and actual or imminent danger which threatens the life of the nation.

*Article 70.* Although protections against arbitrary arrest and detention (Art. 9) and the right to a fair and public hearing in the determination of a criminal charge (Art. 14) may be subject to legitimate limitations if strictly required by the exigencies of an emergency situation, the denial of certain rights fundamental to human dignity can never be strictly necessary in any conceivable emergency. E/CN.4/1985/4 (1985).

**Table 6: TB and Freedom from Arbitrary Arrest and Detention**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Persons diagnosed with TB, who have been declared to be noncompliant with TB treatment, are arrested.</li> <li>• Persons arrested for noncompliance with TB treatment are not provided with treatment while in detention.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 9(1)</b> Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.</p>	<p><b>HRC:</b> Noting that in <b>Moldova</b> "under a regulation promulgated in August 2009, persons with tuberculosis may be subjected to forcible detention in circumstances where he or she is deemed to have 'avoided treatment'. In particular, the regulation is unclear as to what constitutes the avoidance of treatment and fails to provide, inter alia, for patient confidentiality or for the possibility for the judicial review of a decision to forcibly detain a patient." Recommending that the State "should urgently review this measure to bring it into line with the Covenant, ensuring that any coercive measures arising from public health concerns are duly balanced against respect for patients' rights, guaranteeing judicial review and patient confidentiality and otherwise ensuring that persons with tuberculosis are treated humanely." CCPR/C/MDA/CO/2 (2009).</p>
<p><b>CAT 16(1)</b> Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article I, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.</p>	<p><b>CAT:</b> Expressing concern in <b>Moldova</b> over legislation providing for forcible detention of persons with tuberculosis deemed to have "avoided treatment," including lack of clarity "as to what constitutes the avoidance of treatment" and failure to provide adequate safeguards and procedural rights with respect to access to legal representation, "regular review of the reasons for detention or for maintaining continued detention, privacy, family and correspondence, confidentiality, data protection, non-discrimination and non-stigmatization." Recommending that the State "should urgently review the regulation on forcible detention of persons with tuberculosis and related policies, and bring them into compliance with the Convention, in particular guaranteeing independent regular review of detention measures, patient confidentiality and privacy, as well as non-discrimination in their application." CAT/C/MDA/CO/2 (2010).</p>

Human Rights Standards	Case Law
<p><b>ECHR 5(1)</b> Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:</p> <p>(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants.</p>	<p><b>ECtHR:</b> Holding that the involuntary placement in the hospital of an HIV-positive gay man to prevent him from spreading HIV to others violated Art. 5. The Court developed criteria for determining whether a State Party's compulsory isolation of an individual to control infectious disease satisfies ECHR 5: "The detention of an individual is such a serious measure that it is only justified where other, less severe measures have been considered and found to be insufficient to safeguard the individual or the public interest which might require that the person concerned be detained. That means that it does not suffice that the deprivation of liberty is in conformity with national law, it must also be necessary in the circumstances . . . and in accordance with the principle of proportionality ..." Case of <i>Enhorn v. Sweden</i>, 56529/00 (Jan. 25, 2005).</p>

## Table 6 (cont.)

### Other Interpretations

#### **Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):**

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection.... [S]uch detention often takes place without the benefit of sufficient due process, legal safeguards or judicial review. The deprivation of liberty without due process is an unacceptable violation of internationally recognised human rights standards.

#### **WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011):**

*Recommendation 6.* Patients with MDR-TB should be treated using mainly ambulatory care rather than models of care based principally on hospitalization....

**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):** *Involuntary isolation and detention as last-resort measures.* Isolation or detention should be limited to exceptional circumstances.... Isolation or detention should never be implemented as a form of punishment. Patients who decline treatment and who pose a risk to others should be made aware in advance that their continued refusal may result in compulsory isolation or detention....

If, in a rare individual case, a judgement is made that involuntary isolation or detention is the only reasonable means of safeguarding the public, it is essential to ensure that the manner in which isolation or detention is implemented complies with applicable ethical and human rights principles. As set forth in the Siracusa Principles, this means that such measures must be:

- in accordance with the law;
- based on a legitimate objective;
- strictly necessary in a democratic society;
- the least restrictive and intrusive means available; and
- not arbitrary, unreasonable, or discriminatory....

In order to make sure that these principles are followed, countries should review their public health laws to ensure that they carefully limit the scope of government authority and provide due process protections for individuals whose liberty may be restricted. In addition, in order to minimize the danger of arbitrary enforcement, countries and TB programmes should develop clear criteria and procedures for the use of non-voluntary measures, with involvement from TB patients and civil society.

#### **WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):**

In this regard, if a patient willfully refuses treatment and, as a result, is a danger to the public, the serious threat posed by XDR-TB means that limiting that individual's human rights may be necessary to protect the wider public. Therefore, interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. *This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.* A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal.

**Patients' Charter for Tuberculosis Care (World Care Council, 2006):** *Justice.* The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly. The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome.

#### **Siracusa Principles (UN Economic and Social Rights Council, 1985):**

*Article 25.* Public health may be invoked as a ground for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.

*Article 26.* Due regard shall be had to the international health regulations of the World Health Organization.

*Article 39.* A state party may take measures derogating from its obligations under [ICCPR Art. 4] only when faced with a situation of exceptional and actual or imminent danger which threatens the life of the nation....

*Article 70.* Although protections against arbitrary arrest and detention (Art. 9) and the right to a fair and public hearing in the determination of a criminal charge (Art. 14) may be subject to legitimate limitations if strictly required by the exigencies of an emergency situation, the denial of certain rights fundamental to human dignity can never be strictly necessary in any conceivable emergency. E/CN.4/1985/4 (1985).

**Table 7: TB and the Right to a Fair Trial**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Individuals with TB are detained without adequate justification that it is the least restrictive alternative, strictly necessary or a measure of last resort</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 14(1)</b> All persons shall be equal before the courts and tribunals. In the determination of any criminal charge against him, or of his rights and obligations in a suit at law, everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law...</p> <p><b>14(3)</b> In the determination of any criminal charge against him, everyone shall be entitled to... minimum guarantees, in full equality...</p>	None.

**Other Interpretations****Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):**

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection.... [S]uch detention often takes place without the benefit of sufficient due process, legal safeguards or judicial review. The deprivation of liberty without due process is an unacceptable violation of internationally recognised human rights standards.

**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*Involuntary isolation and detention as last-resort measures.* In order to make sure that these principles are followed, countries should review their public health laws to ensure that they carefully limit the scope of government authority and provide due process protections for individuals whose liberty may be restricted. In addition, in order to minimize the danger of arbitrary enforcement, countries and TB programmes should develop clear criteria and procedures for the use of non-voluntary measures, with involvement from TB patients and civil society.

**WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):**

... [I]nterference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. *This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.* A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal.

**Patients' Charter for Tuberculosis Care (World Care Council, 2006):**

*Justice.* The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly. The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome.

**Siracusa Principles (UN Economic and Social Rights Council, 1985):**

*Article 25.* Public health may be invoked as a ground for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.

*Article 26.* Due regard shall be had to the international health regulations of the World Health Organization.

*Article 39.* A state party may take measures derogating from its obligations under [ICCPR Art. 4] only when faced with a situation of exceptional and actual or imminent danger which threatens the life of the nation....

*Article 70.* Although protections against arbitrary arrest and detention (Art. 9) and the right to a fair and public hearing in the determination of a criminal charge (Art. 14) may be subject to legitimate limitations if strictly required by the exigencies of an emergency situation, the denial of certain rights fundamental to human dignity can never be strictly necessary in any conceivable emergency. E/CN.4/1985/4 (1985).

## Table 8: TB and the Right of All Persons Deprived of Their Liberty to be Treated with Humanity

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Prisoners diagnosed with TB are not provided medical treatment or medicines.</li> <li>• Prisoners are detained in facilities that are overcrowded and/or have poor hygiene.</li> <li>• Prisoners diagnosed with TB are not provided adequate nutrition.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 10(1)</b> All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.</p>	<p><b>HRC:</b> Expressing concern to <b>Moldova</b> at the conditions in detention facilities, including the prevalence of disease. The Committee “reminds the State party of its obligation to ensure the health and life of all persons deprived of their liberty. Danger to the health and lives of detainees as a result of the spread of contagious diseases and inadequate care amounts to a violation of article 10 of the Covenant and may also include a violation of articles 9 and 6.” The Committee recommends that Moldova prevent the spread of disease in detention facilities and provide “appropriate medical treatment to persons who have contracted diseases, either in prison or prior to their detention.” CCPR/CO/75/MDA (2002).</p> <p><b>HRC:</b> Expressing concern to <b>Georgia</b> about the large number of cases of tuberculosis reported in prisons and specifically urges the State to “improve the hygiene, diet and general conditions of detention and provide appropriate medical care to detainees as provided for in article 10 of the Covenant.” CCPR/CO/74/GEO (2002).</p> <p><b>HRC:</b> Expressing concern to <b>Ukraine</b> at the “high incidence of HIV/AIDS and tuberculosis among detainees in facilities of the State party is also a cause for concern, along with the absence of specialized care for pre-trial detainees” and recommending that the State “should guarantee the right of detainees to be treated humanely and with respect for their dignity, particularly by relieving overcrowding, providing hygienic facilities, and assuring access to health care and adequate food.” CCPR/C/UKR/CO/6 (2006).</p>

### Other Interpretations

#### Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection....

The UN entities... call on States that operate compulsory drug detention and rehabilitation centres to close them without delay and to release the individuals detained. Upon release, appropriate health care services should be provided to those in need of such services, on a voluntary basis, at community level [including] HIV and TB prevention, treatment, care and support....

Where a State is unable to close the centres rapidly, without undue delay, we urge... [the] provision of health care services pending closure of the centres, including for treatment of HIV and other sexually transmitted infections (STIs), TB and opportunistic infections...

#### Time to act to prevent and control tuberculosis among inmates (International Union Against Tuberculosis and Lung Disease, 2012):

Urging health authorities, technical agencies, civil society organisations and donor agencies to:

- i) adapt and implement the... Stop TB strategy in penitentiary settings;
- ii) conduct screening of new inmates, periodic screening of prisoners and penitentiary services staff to detect active TB in a timely manner, and ensure contact tracing;
- iii) ensure airborne infection control, including protective measures for staff,<sup>8</sup> and promote provider-initiated HIV testing and counselling to detect HIV and TB-HIV co-infected individuals...;
- iv) provide access to early diagnosis and effective treatment of all types of TB, including ensure early initiation of antiretroviral therapy for people living with HIV who have active TB;
- vi) ... provide preventive therapy both for those individuals who become infected with TB in penitentiary services and for those found to be infected while in penitentiary services;

- vii) ensure a continuum of care for released prisoners... and for individuals who are on treatment for either infection or disease before entering the penitentiary services;
- viii) monitor the TB and TB-HIV situation in the penitentiary services... and link recording and reporting in the penitentiary services to the national health information system;
- ix) encourage and facilitate collaborative efforts between the penitentiary and civilian health services;
- x) provide psychological counselling and support for prisoners to improve TB and HIV treatment adherence;
- xi) ... rais[e] awareness about TB among prisoners and penitentiary medical and non-medical staff through continuing education;
- xii) and promote operational research to build evidence for enhanced TB prevention, control and care in penitentiary services.

**Women’s health in prison: Action guidance and checklists to review current policies and practices (WHO, UNODC, 2011):**

*Para. 1.* The underlying importance of human rights should underpin all thinking and all policy development for all those in compulsory detention.

*Para. 3.* Key services to be provided should include... specialist health care, which is readily provided and adjusted to meet the needs of women, such as for... chronic health conditions, HIV and AIDS (including counselling and support), hepatitis, tuberculosis (TB) and other infectious diseases.

**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*Involuntary isolation and detention as last-resort measures.* Isolation or detention should never be implemented as a form of punishment.... In the rare event that isolation or detention is to be used, it must take place in adequate settings, with appropriate infection control measures, as specified more fully in WHO guidance. In addition, reasonable social supports should be provided to isolated patients and their dependants, taking into account the local system’s capacity.

**The Madrid Recommendation (WHO, 2010):** Recognizing the urgent need in all prison systems for “measures to use alternatives to imprisonment where possible and to reduce overcrowding in prisons”, “counselling, screening and treatment programmes for infectious diseases, including HIV/AIDS, tuberculosis, hepatitis B and C and sexually transmitted infections”; “guaranteed throughcare for prisoners upon entry and after release from prison” and “ training of all prison staff in the prevention, treatment and control of communicable diseases”.

**Guidelines for control of tuberculosis in prisons (USAID, Tuberculosis Coalition for Technical Assistance, International Committee of the Red Cross, 2009).**

**WHO Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users (WHO, 2008):**

*Recommendation 11.* Medical examination upon entry and any time thereafter, conforming to internationally accepted standards of medical confidentiality and care, should be available for all prisoners. Prisoners should obtain health care equivalent to that provided for the civilian population, and care should be continuous on transfer in and out of places of detention.

**Principles and Best Practices on the Protection of Persons Deprived of Liberty in the Americas (IACHR, 2008):**

*Principle X.* Persons deprived of liberty shall have the right to health, understood to mean the enjoyment of the highest possible level of physical, mental, and social well-being, including... special measures to meet the particular health needs of persons deprived of liberty belonging to vulnerable or high risk groups, such as... people living with HIV-AIDS, tuberculosis...

**Patients’ Charter for Tuberculosis Care (World Care Council, 2006):**

*Care.* The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness. The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care, centering on patient needs, including those with [MDR-TB] or [TB-HIV] coinfections and preventative treatment for young children and others considered to be at high risk.

## Table 9: TB and Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Institutional settings are overcrowded and unhygienic, making it more likely for individuals to contract TB.</li> <li>• Prisoners cannot access medical treatment and care for a TB diagnosis.</li> <li>• Prisoners are not screened or tested for TB.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CAT 16(1)</b> Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article I, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.</p>	<p><b>CAT:</b> Expressing concern to <b>Zambia</b> at the prevalence of tuberculosis and the high contamination rate of inmates and prison officers due to overcrowding and the lack of adequate health care. Recommending that the State speed up the establishment of health care services in prisons including the recruitment of medical personnel, as established under the Prisons Act of 2004. CAT/C/ZMB/CO/2 (2008).</p> <p><b>CAT:</b> Urging <b>Ethiopia</b> to “take urgent measures to bring the conditions of detention in police stations, prisons and other places of detention into line with the Standard Minimum Rules for the Treatment of Prisoners, as well as with other relevant standards, in particular by... Improving the quality and quantity of food and water as well as the health care provided to detainees and prisoners, including ... tuberculosis patients.” CAT/C/ETH/CO/1 (2011).</p> <p><b>CAT:</b> Expressing concern to <b>Russia</b> about the distressing conditions of pre-trial detention, including the prevalence of tuberculosis and other diseases, as well as the poor and unsupervised conditions of detention in IVS (temporary police detention), and SIZOs (pre-trial establishment) facilities, and recommending “Urgent consideration should be given to making a medical examination compulsory for persons when they enter IVS and SIZOs.” CAT/C/CR/28/4 (2002).</p> <p><b>CAT:</b> Recommending that <b>Estonia</b> “should provide adequate food to all detainees and improve the health and medical services in detention facilities, including by making available appropriate treatments, especially to HIV and tuberculosis infected detainees.” CAT/C/EST/CO/4 (2008).</p> <p><b>CAT:</b> Expressing concern to <b>South Africa and Ukraine</b> about the high rate of tuberculosis amongst detainees and recommending that the State should “adopt effective measures to improve the conditions in detention facilities, reduce the current overcrowding and meet the fundamental needs of all those deprived of their liberty, in particular regarding health care” CAT/C/ZAF/CO/1 (2006); CAT/C/UKR/CO/5 (2007).</p> <p><b>CAT:</b> Expressing concern to <b>Georgia</b> about the “high number of deaths reported from tuberculosis” and encouraging the State to “continue its cooperation with the International Committee of the Red Cross and non-governmental organizations with regard to the implementation of programmes related to the treatment of tuberculosis and distribution and monitoring of the medicines taken in penitentiary facilities throughout its territory.” CAT/C/GEO/CO/3 (2006).</p>



Table 9 (cont.)

Human Rights Standards	Treaty Body Interpretation
	<p><b>SPT:</b> Recommending to <b>Paraguay</b> and <b>Honduras</b> “that all prisoners should have the opportunity to be X-rayed for tuberculosis using mobile X-ray units and that treatment should commence for inmates who have tested positive. Prisoners sharing a cell with a person infected with tuberculosis should be allowed to undergo a second X-ray and the Mantoux test (for prisoners who have not been vaccinated) three months later. This procedure should be repeated periodically to prevent the outbreak of further cases.” CAT/OP/PRY/1 (2010), CAT/OP/HND/1 (2010).</p>
Human Rights Standards	Case Law
<p><b>ECHR 3</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.</p>	<p><b>ECtHR:</b> Finding a violation of Article 3 because “the applicant had to spend twenty three hours per day in an overcrowded cell”. However, the Court noted that contracting TB in detention alone would not necessarily establish an Article 3 violation and dismissed this portion of the applicant’s claim due to a lack of evidence establishing inadequate medical care for his TB. <i>Asyanov v. Russia</i>, Application No. 25462/09 (Jan. 9, 2013).</p> <p><b>ECtHR:</b> Finding a violation of Article 3 because “the applicant did not receive comprehensive, effective and transparent medical assistance in respect of his HIV and tuberculosis in detention. It believes that, as a result of this lack of adequate medical treatment, the applicant was exposed to prolonged mental and physical suffering diminishing his human dignity. The authorities’ failure to provide the applicant with the requisite medical care amounted to inhuman and degrading treatment within the meaning of Article 3 of the Convention.” <i>Koryak v. Russia</i>, Application No. 24677/10 (Nov. 13, 2012).</p> <p><b>ECtHR:</b> Finding a violation of Article 3 on account of the authorities’ failure to duly diagnose the applicant with tuberculosis and comply with their responsibility to ensure adequate medical assistance for him during his detention in a correctional colony before September 2004. <i>Vasyukov v. Russia</i>, Application No. 2974/05 (April 5, 2011).</p> <p><b>ECtHR:</b> Finding that the authorities violated their obligations under Article 3 because there was a “lack of a comprehensive approach to the applicant’s medical supervision and treatment for tuberculosis and HIV and failure to ensure physical conditions reasonably adapted for his recovery process.” <i>Logvinenko v. Ukraine</i>, Application No. 13448/07 (Oct. 14, 2010).</p> <p><b>ECtHR:</b> Finding a violation of Article 3 on account of detention conditions in a pretrial detention center (e.g., overcrowding, sleep deprivation and lack of natural light and air) and the authorities’ failure to provide timely and appropriate medical assistance to the applicant in respect of his HIV and TB infections. <i>Yakovenko v Ukraine</i>, Application No. 15825/06 (Oct. 25, 2007) (adapted from Human Rights in Patient Care: A Practitioner Guide, <a href="http://www.health-rights.am/practitioner-guide">www.health-rights.am/practitioner-guide</a>)</p>

### Other Interpretations

**SR Torture (2013):** Noting that compulsory detention of TB patients, as is reported in certain countries, constitutes a form of abuse in the health care setting: “Medical care that causes severe suffering for no justifiable reason can be considered cruel, inhuman or degrading treatment or punishment, and if there is State involvement and specific intent, it is torture.” *Paras. 39–40. A/HRC/22/53* (2013).

**Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):**

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection.... [S]uch detention often takes place without the benefit of sufficient due process, legal safeguards or judicial review. The deprivation of liberty without due process is an unacceptable violation of internationally recognised human rights standards.

**Table 10: TB and the Right to Privacy**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Information about a patient's TB status is disclosed</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<b>ICCPR 17(1)</b> No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.	None.

**Other Interpretations**

**Recommendations to ensure the diagnosis and treatment of tuberculosis in undocumented migrants (Int'l Union Against Tuberculosis and Lung Disease, 2008):**

*Recommendation 1.* Health authorities and/or health staff should: a) ensure easy access to low-threshold facilities where undocumented migrants who are tuberculosis suspects can be diagnosed and treated without giving their names and without fear of being reported to the police or migration officials, b) remind health staff that they have an obligation to respect confidentiality.

**Patients' Charter for Tuberculosis Care (World Care Council, 2006):**

*Confidence.* The right to have personal privacy, dignity, religious beliefs, and culture respected. The right to have information relating to the medical condition kept confidential and released to other authorities contingent upon the patient's consent.

**Table 11: TB and Freedom of Expression and the Right to Information**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>People who are illiterate may have less knowledge of TB and its signs and symptoms</li> <li>Health care workers fail to give adequate information to patients on the importance of adhering to TB medicine and the possible side effects</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<b>ICCPR 19(1)</b> Everyone shall have the right to hold opinions without interference.  <b>19(2)</b> Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.	None.

## Table II (cont.)

### Other Interpretations

#### **WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*Information, counselling and the role of consent.* Individuals who undergo TB testing should receive basic information about the nature of TB and why they are being tested. Individuals who are offered TB treatment should be given information about the risks and benefits of the proposed interventions (for both the patient and others in the community), the importance of completing the full course of treatment and of infection control measures, and available support to help patients complete the full course of treatment.

*The gap between the availability of drug susceptibility testing and access to M/XDR-TB treatment.* For countries that are still scaling up their capacity to supply rapid drug susceptibility testing, decisions about how to treat patients should be made on an individualized basis, taking into account both the local epidemiology and patient-specific factors. These decisions should ideally be made in a consultative process, involving multiple practitioners and, when available, a patient advocate. Education and counselling should be offered to patients.

#### **Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):**

*Para. 1(j).* Undertake “effective advocacy, communication and social mobilization, avoiding stigmatization and discrimination, and spreading community awareness about policies and plans for prevention and control of tuberculosis including [MDR- and XDR-TB]”.  
*Resolution WHA 62.15.*

#### **WHO Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users (WHO, 2008):**

*Recommendation 6.* All services dealing with drug users should have a case-finding protocol for TB and HIV so that personnel are aware of the symptoms of TB and HIV and can ensure that drug users have access to appropriate TB and HIV testing and counselling, preferably at the service where they initially present.

*Recommendation 9.* All personnel working with TB suspects and patients, people living with HIV and drug users should be able to assess risk factors for HIV infection and transmission and should provide comprehensive HIV prevention information and services to their clients to minimize these risks. Personnel should also be aware of how to protect themselves from occupational exposure to HIV and TB.

#### **Patients’ Charter for Tuberculosis Care (World Care Council, 2006):**

*Care.* The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

*Choice.* The right to a second medical opinion, with access to previous medical records. The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease. The right to choose whether or not to take part in research programs without compromising care.

*Information.* The right to information about what healthcare services are available for tuberculosis and what responsibilities, engagements, and direct or indirect costs are involved. The right to receive a timely, concise, and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives. The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects, and its possible impact on other conditions or treatments. The right of access to medical information which relates to the patient’s condition and treatment and to a copy of the medical record if requested by the patient or a person authorized by the patient. The right to meet, share experiences with peers and other patients and to voluntary counseling at any time from diagnosis through treatment completion.

#### **International Standards for Tuberculosis Care (Tuberculosis Coalition for Technical Assistance, 2006):**

*Standard 9.* To foster and assess adherence, a patient-centered approach to administration of drug treatment, based on the patient’s needs and mutual respect between the patient and the provider, should be developed for all patients. Supervision and support should be gender-sensitive and age-specific and should draw on the full range of recommended interventions and available support services, including patient counseling and education....

**Table 12: TB and Freedom of Assembly and Association**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• TB patients under quarantine or isolation or in detention are from association with others</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 21.</b> The right of peaceful assembly shall be recognized. No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.</p> <p><b>22(1).</b> Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests.</p>	None.

**Other Interpretations****WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*Overarching goals and objectives.* TB patients have the right to receive advice and treatment that meets international quality standards, be free of stigmatization and discrimination, establish and join peer support networks, and benefit from accountable representation.

*The obligation to provide access to TB services.* Focusing on patients as part of their larger communities—Patients should be encouraged to form support groups and to work with their communities to address the social determinants of TB.

**Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):**

*Para. 1(j).* Undertake “effective advocacy, communication and social mobilization, avoiding stigmatization and discrimination, and spreading community awareness about policies and plans for prevention and control of tuberculosis including [MDR- and XDR-TB]”.  
*Resolution WHA 62.15.*

**Patients’ Charter for Tuberculosis Care (World Care Council, 2006):**

*Care.* The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

*Information.* The right to meet, share experiences with peers and other patients and to voluntary counseling at any time from diagnosis through treatment completion.

*Organization.* The right to join, or to establish, organizations of people with or affected by tuberculosis and to seek support for the development of these clubs and community-based associations through the health providers, authorities, and civil society. The right to participate as “stakeholders” in the development, implementation, monitoring, and evaluation of tuberculosis policies and programs with local, national, and international health authorities.

## Table 13: TB and the Right to Enjoy the Benefits of Scientific Progress and its Applications

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• TB patients in resource-constrained settings may have limited access to high-quality diagnostic services and first- and second-line medicines for treatment</li> <li>• Restrictive intellectual property regimes limit access to quality, affordable anti-TB medicines</li> </ul>	

Human Rights Standards	Treaty Body Interpretation
ICESCR 15(1)(b) The States Parties to the present Covenant recognize the right of everyone... [t]o enjoy the benefits of scientific progress and its applications...	None.

### Other Interpretations

**SR Cultural Rights (2012):** *Para. 61.* The Special Rapporteur notes that new incentives have been proposed to ensure innovation and access to medicines at affordable costs, in particular for those living in extreme poverty. Importantly, the WTO Doha Declaration on the TRIPS Agreement and public health explicitly recognizes that the TRIPS Agreement “can and should be interpreted and implemented in a manner supportive of WTO Members’ right to protect public health”, and reaffirmed the right to use the flexibilities included in the Agreement for this purpose. *A/HRC/20/26 (2012).*

**WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011):** Extensive discussion of prevention, treatment and care options for MDR- and XDR-TB, including HIV-coinfection.

**WHO Model List of Essential Medicines (WHO, 2011).**

**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*The gap between the availability of drug susceptibility testing and access to M/XDR-TB treatment.* Countries that implement diagnostic testing in the absence of treatment should do so only as a temporary measure, and should establish a timetable for when treatment for M/XDR-TB will be made available.... As emphasized above, countries and TB programmes should provide universal, free access to drug susceptibility testing; for resource-constrained countries that cannot meet this obligation on their own, the international community should give financial and other support.

*Research on TB care and control.* There is an urgent need to develop an enhanced evidence base for TB prevention and treatment, and to improve the standard of care. Achieving these goals will be impossible without a greater commitment to research.... The international community should cooperate to develop incentives to encourage this kind of research and development. It is also important to ensure that, as evidence is developed, it is made publicly available and integrated into practice.

**WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):**

WHO places prevention and care of XDR-TB as a priority through the strengthening of basic TB control and the necessary interventions to cure existing cases.... [This] includes ensuring that the capacity to identify and treat drug-resistant TB is in place, with a secure supply of second-line anti-TB drugs required for treating multidrug-resistant TB obtained through the Green Light Committee (in resource-limited settings).... WHO strongly recommends that governments must ensure, as their top priority, that every patient has access to high quality TB diagnosis and treatment for TB and drug-resistant forms of TB.

**Berlin Declaration on Tuberculosis (WHO European Ministerial Forum, 2007)**

*Para. 5(2).* We will adopt the Stop TB Strategy in all its components, thereby... allowing and promoting research into and the development of new diagnostics, drugs and vaccines, as well as programme-based operational research. *EUR/07/5061622/5 (2007).*

**Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria, Resolutions 2005/23, 2004/26, 2003/29 & 2002/32 (UN Commission on Human Rights).**

**General Comment No. 17: The right of everyone to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author (art. 15 (1) (c)) (CESCR, 2006):**

States parties should ensure that their intellectual property regimes constitute no impediment of their ability to comply with their core obligations in relation to the right to health ... States thus have a duty to prevent that unreasonably high license fees or royalties for access to essential medicines ... undermine the right ... of large segments of the population to health ... *E/C.12/GC/17 (2006).*

## Table 13 (cont.)

### Other Interpretations

**Political Declaration on HIV/AIDS (UN General Assembly, 2006):**

*Para. 33.* Emphasize the need for accelerated scale-up of collaborative activities on tuberculosis and HIV, in line with the Global Plan to Stop TB 2006–2015, and for investment in new drugs, diagnostics and vaccines that are appropriate for people with TB-HIV co-infection.

**Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):**

*Research and Development.* To promote and support research and development of microbicides, vaccines, diagnostics and treatment for HIV and AIDS, TB and malaria, including traditional medicine. Sp/Assembly/ATM/2 (I) Rev.3 (2006).

**Doha Declaration on the TRIPS Agreement and Public Health (World Trade Organization, 2001):**

*Para. 4.* [T]he TRIPS agreement does not and should not prevent Members from taking measures to protect public health ... in particular to promote access to medicines for all.... Each member has the right to grant compulsory licences and the freedom to determine the grounds upon which such licences are granted...[and] the right to determine what constitutes a national emergency or other circumstances of extreme urgency, it being understood that public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics, can represent a national emergency or other circumstances of extreme urgency. WT/MIN(01)/DEC/2 (2001).

**Amsterdam Declaration to Stop TB (WHO Ministerial Conference on “TB and Sustainable Development”, 2000):**

*Part V.* [A]ccelerate basic & operational research for the development & delivery of new tools, including diagnostics, drugs & vaccines, & pay attention to the need for improved incentives for drug & vaccine development in a manner consistent with affordability & accessibility of such new products

## Table 14: TB and the Rights of Women

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Women have less decision-making power over the use of household resources</li> <li>• Women may not leave the house to seek care without the company of a male relative</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 12(1)</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p>	<p><b>CEDAW:</b> Recommending that <b>Kyrgyzstan</b> “strengthen measures to reduce ... the spread of tuberculosis and other diseases among women.” CE-DAW/C/KGZ/CO/3 (2008).</p> <p><b>CEDAW:</b> Expressing concern to the increase of tuberculosis among women to <b>Estonia A/57/38(SUPP)</b> (2002), <b>Vietnam A/56/38(SUPP)</b> (2001), and <b>Lithuania A/55/38(SUPP)</b> (2000).</p>

### Other Interpretations

**UN Commission on the Status of Women (2011):** Calls on Governments to integrate HIV prevention, voluntary counselling and voluntary testing of HIV into other health services, including sexual and reproductive health, family planning, maternity and tuberculosis services. *Resolution 55/2* (2011).

**Women’s health in prison: Action guidance and checklists to review current policies and practices (WHO, UNODC, 2011):**

*Para. 1.* The underlying importance of human rights should underpin all thinking and all policy development for all those in compulsory detention.

*Para. 3.* Key services to be provided should include... specialist health care, which is readily provided and adjusted to meet the needs of women, such as for... chronic health conditions, HIV and AIDS (including counselling and support), hepatitis, tuberculosis (TB) and other infectious diseases....

**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*The obligation to provide access to TB services.* Interventions should be gender-sensitive and address different types of vulnerabilities.... In addition, the needs of women, children, and people coinfecting with HIV warrant special consideration.

## Table 14 (cont.)

### Other Interpretations

**Agreed Conclusions of the Commission on the Status of Women on the Critical Areas of Concern of the Beijing Platform for Action 1996-2009 (UN DESA, 2010):** Recommending that governments, the UN system and civil society undertake measures to: “[i]ncrease the preventive, as well as the therapeutic, measures against **tuberculosis** and malaria”; intensify “support of national efforts against HIV/AIDS, particularly in favour of women and young girls, including efforts to provide affordable antiretroviral drugs, diagnostics and **drugs to treat tuberculosis** and other opportunistic infections”; “incorporate gender perspectives and human rights in health-sector policies and programmes”; and “recognize that the lack of economic empowerment and independence increased women’s vulnerability to a range of negative consequences, involving the risk of contracting HIV/AIDS, malaria, **tuberculosis** and other poverty-related diseases” ST/ESA/327 (2010).

**Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):**

*Para. 4.* Urging member states “to increase investment by countries and all partners substantially in operational research and research and development for new diagnostics, medicines and vaccines to prevent and manage tuberculosis including multidrug-resistant and extensively drug-resistant tuberculosis”. *Resolution WHA 62.15.*

**Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):**

*Para. 1(i).* ...[S]upporting developing countries to establish manufacturing plants to produce combined preparations of anti-TB medicines ... to ensure adequate drug supply for the prevention and control of M/XDR-TB.

## Table 15: TB and the Rights of Children

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Children are malnourished and at risk of TB infection</li> <li>• Children live in households affected by TB</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(1)</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p><b>CRC:</b> Expressing concern to <b>Portugal</b> that “Infant mortality, under-5 mortality and child tuberculosis rates remain higher than the regional average, particularly in some northern rural areas, and are also too high in the Azores” and recommending that the State “[i]ncrease investment in public health care facilities, including investments by civil society” and “[e]nsure the equal access of all children to the highest attainable standard of health care in all areas of the country.” CRC/C/15/Add.162 (2001).</p>



Table 15 (cont.)

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(1)</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p><b>CRC:</b> Expressing concern to <b>Uzbekistan</b> “at the increasing number of children infected with preventable diseases, such as Tuberculosis ...” and recommending that the State “[c]ontinue its reform of the health sector and its efforts to strengthen the primary care centres and the preventive health services.” CRC/C/ UZB/CO/2 (2006).</p> <p><b>CRC:</b> Expressing concern in <b>Armenia</b> about “the continuous growth in tuberculosis morbidity among children” and recommending that the government “[t]ake measures to reduce child and infant mortality rates and combat tuberculosis.” CRC/C/15/Add.225 (2004).</p> <p><b>CRC:</b> Expressing concern <b>Gabon</b> that it continues “to be threatened by early childhood diseases such as ... tuberculosis” and recommending that it “[r]einforce its efforts to allocate appropriate resources and develop and implement comprehensive policies and programmes to improve the health situation of children, particularly in rural areas” and “[f]acilitate greater access to primary health service.” CRC/C/15/Add.171 (2002).</p> <p><b>CRC:</b> Expressing concern to <b>Uzbekistan</b> at the “high incidence of infectious diseases, such as tuberculosis, despite high rates of immunization” and recommending the State “[i]mplement the 2000 Amsterdam Declaration to Stop TB.” CRC/C/15/Add.167 (2001).</p> <p><b>CRC:</b> Expressing concern to <b>Ethiopia</b> “at the high incidence of malaria and tuberculosis and their effects upon children, at the fragile health infrastructure, limited health awareness among the public and the limited implementation of the 1993 Health Policy and the 1994 Social Policy” and urging the State to “ensure that access to primary health care services is increased, that national health infrastructure is strengthened and that public health education programmes are used to lower infant mortality rates and raise life expectancy in the State party.” CRC/C/15/Add.144 (2001).</p> <p><b>CRC:</b> Expressing concern to <b>Lithuania</b> “at the high rates of child morbidity, in particular the increase in cases of tuberculosis” and recommending that the State “allocate appropriate resources and develop comprehensive policies and programmes to improve the health situation of all children.” CRC/C/15/Add.146 (2001).</p> <p><b>CRC:</b> Noting that <b>Mauritania</b> has a “resurgence of tuberculosis” and recommending that the State “[a]llocate appropriate resources and develop comprehensive policies and programmes to improve the health situation of all children without discrimination, in particular by focusing more on primary care and further decentralizing the health care system.” CRC/C/15/ADD.159 (2001).</p> <p><b>CRC:</b> Noting that <b>Moldova</b> has a “high incidence of tuberculosis ... in schoolchildren” and recommending that the State “[d]efine sustainable financing mechanisms for the health care system, including adequate salaries for child health care professionals, in order to ensure that all children, in particular children from the most vulnerable groups, have access to free basic health care of good quality.” CRC/C/15/Add.192 (2002).</p>

## Table 15 (cont.)

### Other Interpretations

**WHO Model List of Essential Medicines, Children (WHO, 2011).**

**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

*The obligation to provide access to TB services.* Interventions should be gender-sensitive and address different types of vulnerabilities.... In addition, the needs of women, children, and people coinfecting with HIV warrant special consideration.

**WHO Guidelines for the programmatic management of drug-resistant tuberculosis: Emergency Update (WHO, 2008):** Extensive discussion of TB prevention, treatment and care options for children. Select recommendations:

9.5 *Children.* ...Anecdotal evidence suggests that adolescents are at high risk for poor treatment outcomes. Early diagnosis, strong social support, individual and family counselling and a close relationship with the medical provider may help to improve outcomes in this group.

**WHO Guidance for national tuberculosis programmes on the management of tuberculosis in children (WHO, 2006).**

**Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):**

*Protection of Human Rights.* To continue promoting an enabling policy, legal and social environment that promotes human rights particularly for women, youth and children and ensure the protection of people infected and affected by HIV and AIDS, TB and Malaria....

*Prevention, Treatment, Care and Support.* To invest heavily in evidence-based prevention as the most cost-effective intervention with focus on young people, women, girls and other vulnerable groups. Sp/Assembly/ATM/2 (I) Rev.3 (2006).

**Patients' Charter for Tuberculosis Care (World Care Council, 2006):**

*Care.* The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness.

**CRC, General Comment 3 (2003):** "In the context of HIV/AIDS and taking into account the evolving capacities of the child, States parties are encouraged to ensure that health services employ trained personnel who fully respect the rights of children to privacy (art. 16) and non-discrimination in offering them... HIV-related care and treatment if and when needed, including for the prevention and treatment of health problems related to HIV/AIDS, e.g. tuberculosis and opportunistic infections." CRC/GC/2003 (2003)

### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>211</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>212</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>213</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>214</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>211</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>212</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>213</sup> Ibid

<sup>214</sup> Ibid

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>215</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>215</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

- A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:
- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

## 4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF TB?

This section contains **four examples** of effective human rights-based work in the area of TB and human rights. These are:

1. Defining the grounds for compulsory isolation of a patient with an infectious disease
2. Development of a Patient Network to fight TB in Peru
3. Advocating for the constitutional rights of TB patients in Kenya
4. Litigating for prisoners exposed to TB in South African prisons

## Example I: Defining the grounds for compulsory isolation of a patient with an infectious disease

*Enhorn v. Sweden*, app. No. 56529/00 (Jan. 25, 2005).

Available at: <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-68077>

### Project Type

Litigation

### Actor

Mr. Eie Enhorn suffered from an infectious disease that Swedish law listed as a threat to public health (HIV/AIDS). Pursuant to a national public health law drafted to stem the spread of infectious disease, Sweden ordered the compulsory isolation of Mr. Enhorn. Mrs. E. Hagstrom, a legal aid attorney practicing in Stockholm, represented the interests of Mr. Enhorn before the European Court of Human Rights.

### Problem

Although the petitioner in this case suffered from HIV, the main issue the Court considered concerned the powers of a State Party to the European Convention on Human Rights to order compulsory isolation of an individual with an infectious disease.

This case is centrally important to Europeans who suffer from TB and who are at risk of involuntary detention. Extensively drug-resistant tuberculosis (XDR-TB) and multi-drug resistant tuberculosis (MDR-TB)—in particular—raise the question of whether involuntary detention is justified where voluntary measures have failed or where the patient poses a danger to public health. A number of countries in Europe currently allow for involuntary detention of TB patients (see chart, above)

### Legality of Involuntary Detention of TB Patients in Select European States

	Detention	Isolation on grounds of exposure	Exclusion from activities	Number of control measures
<i>Spain</i>	N	N	N	0
<i>France</i>	N	N	Y	2
<i>Germany</i>	Y	N	N	2
<i>Israel</i>	Y	N	Y	2
<i>Netherlands</i>	N	N	N	2
<i>Finland</i>	N	N	Y	3
<i>Poland</i>	N	N	Y	3
<i>England</i>	Y	N	Y	4
<i>Estonia</i>	Y	N	N	4
<i>Hungary</i>	N	N	Y	4
<i>Switzerland</i>	Y	N	N	4
<i>Czech</i>	Y	N	Y	5
<i>Norway</i>	Y	Y	Y	6
<i>Russia</i>	Y	N	Y	6

Adapted from Coker R, *Public Health Law and Tuberculosis Control in Europe*, Public Health 121, no. 4 [2007]: 266-73).



## Legal Conflict

ECHR, Article 5 § 1

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants.

### The 1988 Infectious Diseases Act (Sweden)

Section 38: “The County Administrative Court, on being petitioned by the county medical officer, shall make an order for the compulsory isolation of a person infected with a disease dangerous to society if that person does not voluntarily comply with the measures needed in order to prevent the infection from spreading. An order of this kind shall also be made if there is *reasonable cause* to suppose that the infected person is not complying with the practical instructions issued and this omission entails a *manifest risk* of the infection being spread. Compulsory isolation shall take place in a hospital run by a county council. (emphasis supplied).

### Procedure

An Administrative Court in Sweden tasked with hearing section 38 actions (see side box) ordered the compulsory isolation of Mr. Enhorn. The Administrative Court of Appeals upheld Mr. Enhorn’s compulsory isolation. Having exhausted his domestic remedies, Mr. Enhorn brought a human-rights claim before the European Court of Human Rights to challenge his compulsory isolation.

### Arguments & Holdings

Existence of “*reasonable cause*” and “*manifest risk*” as required under the domestic law. The state ordered compulsory isolation of the applicant pursuant to section 38 of the Infectious Disease Act (Sweden), which requires *reasonable cause* to suppose that the infected person is not complying with the practical instructions issued. It further requires that this omission entails a *manifest risk* of the infection being spread. The applicant did not create the manifest risk of spreading the disease. The Court, however, found that the applicant’s sexual history, which included the infection of a 19-year-old man, misuse of alcohol and failure to follow instructions of medical professionals provided “*reasonable cause*” to believe that the applicant would not follow future healthcare orders and that his likely omission to follow orders would create a manifest risk of spreading his infection. Therefore, the Court found that the Government satisfied its obligations under section 38, and Mr. Enhorn’s compulsory isolation was legal under Swedish law.

*Whether detention and deprivation of liberty was justified under Article 5 § 1(e).* The Court itself noted that it had scant jurisprudence on the issue of detaining a person “for the prevention of the spreading of infectious diseases.” The Court, therefore, outlined the criteria for determining whether a State Party’s compulsory isolation of an individual to control infectious disease satisfied Article 5 § 1(e) of the European Convention on Human Rights:

The detention of an individual is such a serious measure that it is only justified where other, less severe measures have been considered and found to be insufficient to safeguard the individual or the public interest which might require that the person concerned be detained. That means that it does not suffice that the deprivation of liberty is in conformity with national law, it must also be necessary in the circumstances . . . and in accordance with the principle of proportionality . . . (citations omitted).

The Court found that the Government never provided examples of less severe measures that were shown to be insufficient to safeguard the public health from the risk of infection. Therefore, the Court held that the compulsory isolation of Mr. Enhorn violated Article 5 § 1 of the ECHR.

### Commentary & Analysis

This case is important because it establishes criteria for determining whether the compulsory isolation of an individual with an infectious disease is justified under the ECHR. Isolation in accordance with the national law of a State Party is not sufficient to pass scrutiny under the ECHR. To justify isolation of a TB patient or any other patient on the basis of the health threat posed by their infectious disease, a State Party must show that isolation of the patient is:

- *Necessary*—that the State Party considered less severe measures and found them to be insufficient to safeguard the health of the individual or public; and
- *Proportional*—that the degree and length of isolation is proportional to the threat to the individual's health or public health.

Compulsory detention statutes in Europe, as outlined in the chart above, are susceptible to challenges made on human rights grounds.

The applicant argued that the statute's required showing of "reasonable cause" and "manifest risk" were too vague. The statute lacked clearness and foreseeability, which would allow him to understand what constituted prohibited conduct. In the alternative, he argued that his actions did not create the manifest risk of spreading the disease. The Court, however, found that the applicant's sexual history, which included the infection of a 19-year-old man, misuse of alcohol and failure to follow instructions of medical professionals provided "reasonable cause" to believe that the applicant would not follow future healthcare orders and that his likely omission to follow orders would create a manifest risk of spreading his infection. Therefore, the Court found that the Government satisfied its obligations under section 38, and Mr. Enhorn's compulsory isolation was legal under Swedish law.

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- *Proportional*—that the degree and length of isolation is proportional to the threat to the individual's health or public health.

Compulsory detention statutes in Europe, as outlined in the chart above, are susceptible to challenges made on human rights grounds.

### WHO Opinion

Interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. **This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.**

A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal. The Siracusa principles are:

- The restriction is provided for and carried out in accordance with the law;
- The restriction is in the interest of a legitimate objective general interest;
- The restriction is strictly necessary in a democratic society to achieve the objective;
- There are no less intrusive and restrictive means available to reach the same objective;
- The restriction is based on scientific evidence and not drafted or imposed arbitrarily i.e. in an unreasonable or otherwise discriminatory manner.

Source: [www.who.int/tb/features\\_archive/involuntary\\_treatment](http://www.who.int/tb/features_archive/involuntary_treatment)

Additional Sources: World Health Organization, Report of the Meeting of the WHO Global Task Force on XDR-TB (Oct. 9-10 2006). [www.who.int/tb/challenges/xdr/globaltaskforcereport\\_octo6.pdf](http://www.who.int/tb/challenges/xdr/globaltaskforcereport_octo6.pdf); Geneviève Pinet, World Health Organization, Good Practice in Legislation and Regulations for TB Control: An Indicator of Political Will (2001). [http://apps.who.int/iris/bitstream/10665/68708/1/WHO\\_CDS\\_TB\\_2001.290.pdf](http://apps.who.int/iris/bitstream/10665/68708/1/WHO_CDS_TB_2001.290.pdf)

## Example 2: Development of a Patient Network to fight TB in Peru

### Project Type

Advocacy

### Organization

The Peruvian Patient Network (PPN) formed in 2007 after several months of intense mobilization by patient organizations, human rights groups, and civil society organizations in Peru. PPN has a small staff and an annual budget under USD \$1,000, but it is supported by the Ombudsman of Peru, the Ombudsman at the Ministry of Health, the Peruvian Medical Association and the Pan American Health Organization.

### Problem

Peru has long struggled with tuberculosis (TB). In the 1960s, Peru was estimated to have the highest case rates of TB in Latin America. Incidence and mortality rates fell in the early 1990s, largely due to Peru's implementation of directly observed treatment short (DOTS), the internationally recommended strategy for TB control. But these gains were ephemeral. According to a 2009 report by USAID, "[i]n the past few years, Peru's National TB Program (NTP) has been hindered by serious administrative and funding problems in the Ministry of Health (MOH). These problems led to deterioration of the TB situation . . . ."

### Actions Taken

With ongoing threats to health and human rights in Peru, PPN believes in vigilance, advocacy and the training of advocates:

- *Vigilance.* Helping to guarantee constant access to medicine and to ensure the regulation of patents.
- *Advocacy.* Lobbying the government to promote policies that promote health and prevent illness; seeking additional resources for the first level of health care and leading a declaration of a state of emergency in the health system for non-contagious diseases.
- *Capacity building and training.* Training activists to engage—at the community level—in the decentralization of the health care system, assist in health promotion and access to medicines.

PPN works with other patient organizations, including the National Coalition of Cancer Patients, Mental health Patients and Patients Living with HIV/AIDS. Importantly, PPN also integrates groups of patients with TB and others who have suffered adverse consequences from the health care system. Working together with the government, patients and patient organizations, PPN advocates for human rights within the context of health care.

### Results & Lessons Learned

In 2004, a reorganization of the MOH created the National Sanitary Strategy for the Prevention and Control of Tuberculosis (ESNTBC) to replace the failed NTP. Universal access to multi-drug resistant tuberculosis (MDR TB) diagnosis and treatment is now a reality in Peru.

PPN faced a range of challenges in their interactions with stakeholders and government leaders. Among those challenges were a lack of time and resources. In addition, PPN often found it difficult to compete for the attention of and then convince influential administrators and government leaders who sometimes had conflicting interests. To overcome these challenges, PPN learned that it is important to build and encourage development of regional, national and international networks of patients. Doing so develops information and knowledge, builds capacity, lets voices be heard and increases the status of the organization. A network promotes quality health care services that respect human rights.

#### **Peruvian Network for Patients and Users**

(PROSA, Program for the Self-Help and Support of Seropositive Persons)

Lima, PeruE-mail: [prosa@prosa.org.pe](mailto:prosa@prosa.org.pe)

Website: <http://prosa.org.pe>

## Example 3: Advocating for the constitutional rights of TB patients in Kenya

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### Project Type

Advocacy

### Organization

KELIN is a national network that responds to human rights concerns relating to health, including TB and HIV.

### Problem

In October 2012, a patient at Kenyatta National Hospital in Nairobi was diagnosed with “extensively drug-resistant” tuberculosis (XDR-TB). The patient—known as “Mrs. X” to protect her anonymity—is one of about 600 people confirmed to be living with drug-resistant TB in Kenya. Fewer than half of these patients receive the treatment they need to get better and prevent further spread of the infectious disease. XDR-TB, which has been reported in 69 countries globally, describes strains of tuberculosis that are resistant to the two most powerful anti-TB medicines and at least three of the six classes of secondary medicines. Because of this resistance, treatment can take longer than two years and patients must take medicines that are very difficult for the body to tolerate.

At a policy level, the Kenyan government is committed to giving its citizens the highest attainable standard of health, as enshrined in Article 43(1) of the Constitution. As part of this commitment, the country adopted the WHO’s international standards of TB care and patients’ charter for tuberculosis care, which endorse free TB treatment as a government responsibility. Despite this, Mrs. X was left for four months without receiving proper treatment. She was finally prescribed three expensive medicines, but was forced to pay for two of these herself. The third medicine, Viomycin, is not registered for use in Kenya and was therefore inaccessible to Mrs. X and other patients.

Mrs. X says the situation has put tremendous financial and psychological stress on her and her family. “The way in which I have been treated by the public health service is making it very difficult to survive,” she said. “My family has to find 16,000 shillings (approx. \$200) for drugs every week. All I want is for the government to provide me with the medicine that I need without making me pay for it myself.”

### Actions Taken

Advocates at KELIN have taken on Mrs. X’s case. Working with 15 other civil society organizations, KELIN delivered an advisory note to government ministers and Kenya’s Attorney General outlining the facts of the cause and urging immediate action. In an official statement, KELIN attorney Allan Maleche said, “One of Kenya’s Millennium Development Goals is to reduce the incidence and mortality due to TB by 2015 and to eradicate it completely by 2050, but the Government is not addressing TB with the level of seriousness it deserves, particularly as it is a matter concerning the individual, community, national and global public health.”

### Results & Lessons Learned

Following the civil society action, the Kenyan government agreed in 2012 to provide Mrs. X with the two available TB drugs at no cost, but it stressed that it is unable to guarantee the supply of these drugs beyond a few weeks. Mrs. X needs at least several months of treatment to overcome XDR-TB. She also needs the third medicine, Viomycin, but that remains unavailable in Kenya.

At last report in January 2013, Mrs. X's health was improving. She was responding well to the medication, although she remained concerned about receiving refunds from the Government for the costs of laboratory tests that she has incurred.

Although government efforts to provide some of the necessary drugs are a positive development, concrete actions are needed to improve policies and programs to detect and treat drug-resistant TB and realize the commitments in Kenya's Constitution. Civil society organizations, like those coordinated by KELIN, play an important role to hold governments accountable for designing and implementing policies that meet patients' needs. Without them, it is unlikely that patients like Mrs. X will receive the medications and support needed to get well.

#### **KELIN**

Nairobi, Kenya

Email: [info@kelinkenya.org](mailto:info@kelinkenya.org)

Website: [www.kelinkenya.org](http://www.kelinkenya.org)



## Example 4: Litigating for prisoners exposed to TB in South African prisons

*Lee v. Minister for Correctional Services, Constitutional Court of South Africa*, Case CCT 20/12 [2012] ZACC 30.<sup>216</sup> [www.saflii.org/za/cases/ZACC/2012/30.html](http://www.saflii.org/za/cases/ZACC/2012/30.html).

### Project Type

Litigation

### Actor

Mr. Dudley Lee was incarcerated in Pollsmoor Maximum Security Prison outside Cape Town, South Africa, from 1999 to 2004 on charges of counterfeiting, fraud and money laundering, among others. The prison was at over 200% occupancy and notoriously crowded, with 3 men in single cells and 40 to 60 men in communal cells. Inmates were confined in close contact for as much as 23 hours every day.

Mr. Lee was 53 years old when he entered Pollsmoor and he did not have TB. In June 2003, he was diagnosed with pulmonary TB. According to SECTION27, a public interest law center providing amicus support: “In September 2004—over four years after entering prison—he was acquitted of the charges against him and released. He then sued the Minister of Correctional Services in the Western Cape High Court in Cape Town for negligently causing him to become infected with TB.”

### The Problem

South Africa has one of the highest rates of TB incidence in the world. TB is the country’s leading cause of death and is often compounded by HIV co-infection and drug resistant strains of TB. The risk is especially high in prisons, which combine overcrowding, poor nutrition and sanitation, poor health care, and inadequate infection control measures.

Under the South African Constitution, all individuals—including prisoners—have the right to life, to freedom and security of the person, and to be detained in “conditions of detention that are consistent with human dignity, including at least exercise and the provision, at state expense, of adequate accommodation, nutrition, reading material and medical treatment”. Furthermore, Standing Correctional Orders require prison officials to screen, isolate, separate and treat prisoners infected with or at risk of TB.

In this case, Mr. Lee sued the South African government for negligence in its systemic failure to take preventive and precautionary measures in prison, causing him to be infected with TB. The lawsuit shows how litigation to enforce constitutional and statutory obligations can protect the rights of prisoners at risk of TB.

<sup>216</sup> This case study content is adapted from the case opinions, as well as content from Section 27 ([www.section27.org.za](http://www.section27.org.za)). See *Lee v. Minister of Correctional Services* 2011 (6) SA 564 (WCC) (High Court Judgment), [www.saflii.org/za/cases/ZAWCHC/2011/13.pdf](http://www.saflii.org/za/cases/ZAWCHC/2011/13.pdf); *Minister of Correctional Services v. Lee* 2012 (3) SA 617 (SCA) (Supreme Court of Appeal Judgment), [www.saflii.org/za/cases/ZASCA/2012/23.pdf](http://www.saflii.org/za/cases/ZASCA/2012/23.pdf); and John Stephens, “Dudley Lee v Minister of Correctional Services, what will it mean for South Africa?”, *Health-e*, Aug. 28, 2012. [www.health-e.org.za/news/article.php?uid=20033738](http://www.health-e.org.za/news/article.php?uid=20033738).

## South African Constitution Chapter 2, Bill of Rights

**Section 10.** Everyone has inherent dignity and the right to have their dignity respected and protected.

**Section 11.** Everyone has the right to life.

**Section 12(1).** Everyone has the right to freedom and security of the person, which includes the right:

- (a) not to be deprived of freedom arbitrarily or without just cause;
- (b) not to be detained without trial;
- (c) to be free from all forms of violence from either public or private sources;
- (d) not to be tortured in any way; and
- (e) not to be treated or punished in a cruel, inhuman or degrading way.

**Section 35(2)(e).** Everyone who is detained, including every sentenced prisoner, has the right... to conditions of detention that are consistent with human dignity, including at least exercise and the provision, at state expense, of adequate accommodation, nutrition, reading material and medical treatment....

### Procedure

*High Court.* Mr. Lee filed suit in 2004. The case went to trial in 2009 and 2010. In 2011, the High Court ruled in his favor. It held that prison authorities failed to take adequate, or even any, steps to protect him against the risk of TB—including prevention, diagnosis and treatment measures, as well as adequate staffing, health care and nutrition.

*Supreme Court of Appeal.* In 2012, the Minister appealed to the Supreme Court of Appeal (SCA) which ruled against Mr. Lee. It found that prison authorities were in breach of their duties. However, Mr. Lee could not prove that their negligence caused his TB since he could not identify the “source” of his infection or show that reasonable precautions would have “altogether eliminated” the risk of infection.

*Constitutional Court.* Mr. Lee appealed to the Constitutional Court in 2012. The Treatment Action Campaign, Centre for Applied Legal Studies, and Wits Justice Project, represented by SECTION27, were admitted as amici curiae (friends of the court).

### Arguments and Holdings

The Constitutional Court considered the following issues on the merits: (1) whether the Minister’s negligent conduct caused Mr. Lee to contract TB; (2) if not, whether the common law needed to be developed to give effect to his constitutional rights and to avoid injustice.

The Court found that the SCA applied an unduly inflexible standard in determining the issue of causation. The SCA should have simply considered whether the conditions of Mr. Lee’s incarceration were a more probable cause of his tuberculosis than if the conditions had been different. Instead, the SCA required Mr. Lee to prove that reasonable systemic measures by prison authorities would have totally eliminated the risk of TB—a standard no inmate could ever meet.

The Court upheld Mr. Lee’s claim, noting that important democratic and constitutional issues were at stake:

*The responsible authorities’ function is to execute its duties in accordance with the purposes of the [Correctional Services Act] which include detaining all inmates in safe custody whilst ensuring their human dignity and providing adequate health care services for every inmate to lead a healthy life. The rule of law requires that all those who exercise public power must do so in accordance with the law and the Constitution. This, including the requirements of accountability and responsiveness, provides ‘additional’ reasons for finding in favour of the applicant and imposing delictual liability.*

### **Analysis and Commentary**

This case is an example of an individual bringing a successful claim for constitutional damages against his government for human rights violations in prison. It is also an examples of lawyers and civil society organizations taking an active role in developing jurisprudence on TB-related rights in South Africa.

The decision takes a humane and pragmatic approach to factual causation in cases of negligent omission by prison officials: instead of mechanistically requiring the applicant to prove that proper action would have eliminated all risk of TB, it simply requires him to show that his actual conditions were likely the cause of his TB infection. It takes a similar approach to legal causation as it relates to the positive duty of the state: proper action simply means taking “reasonable measures to reduce the risk of contagion”—here, complying with the statutory obligation to screen, isolate, examine, report, etc.

The decision illustrates a common theme in health and human rights: that flexibility is often essential to ensuring justice for vulnerable individuals, whether it’s in the provision of tailored treatment for MDR-TB patients or in the provision of legal remedies for prisoners with TB. It is therefore very innovative and sets a precedent for developing favorable case law for prisoners with TB.

#### **SECTION27**

Braamfontein, South Africa  
E-mail: [info@section27.org.za](mailto:info@section27.org.za)  
Website: [www.section27.org.za](http://www.section27.org.za)

#### **Treatment Action Campaign (TAC)**

Cape Town, South Africa  
Website: [www.tac.org.za](http://www.tac.org.za)

#### **Wits Justice Project**

South Africa  
Website: [www.witsjusticeproject.com](http://www.witsjusticeproject.com)

## 5. WHERE CAN I FIND ADDITIONAL RESOURCES ON TB AND HUMAN RIGHTS?

A list of commonly used resources on TB and human rights follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Declarations and Statements
- D. Human Rights and TB – General Resources
- E. Right to Non-discrimination
- F. Right to Health
- G. Freedom from Arbitrary Arrest and Detention
- H. Right of All Persons Deprived of their Liberty to be Treated with Humanity
- I. Freedom from Torture or Cruel, Unusual or Degrading Punishment
- J. Right to Privacy
- K. Freedom of Assembly and Association
- L. Right to Enjoy the Benefits of Scientific Progress and its Applications
- M. Rights of Women
- N. Rights of Children
- O. Key Populations – People Living with HIV
- P. Key Populations – People Who Use Drugs
- Q. Key Populations – Refugees and Internally Displaced Persons
- R. Key Populations – Migrant Workers

### A. International Instruments

#### Non-binding

- ILO et al., Joint Statement on compulsory drug detention and rehabilitation centres, ILO, OHCHR, UNDP, UNESCO, UNFPA, UNHCR, UNICEF, UNODC, UN Women, WFP, WHO, and UNAIDS (2012). [www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=11941&LangID=E](http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=11941&LangID=E).
- UN Congress on the Prevention of Crime and the Treatment of Offenders, *Standard Minimum Rules for the Treatment of Prisoners* (1995). [www.umn.edu/humanrts/instreet/g1smr.htm](http://www.umn.edu/humanrts/instreet/g1smr.htm).
- UN Commission on Human Rights, *Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria*, Resolutions 2005/23, 2004/26, 2003/29 & 2002/32. [www.ohchr.org/EN/Issues/HIV/Pages/Documents.aspx](http://www.ohchr.org/EN/Issues/HIV/Pages/Documents.aspx).
- UN Commission on the Status of Women, *Women, the girl child and HIV and AIDS*, Resolution 55/2, E/CN.6/2011/L.3 (2011). [www.un.org/womenwatch/daw/csw/csw55/other-outcomes/HIVandAIDS-adv-unedit.pdf](http://www.un.org/womenwatch/daw/csw/csw55/other-outcomes/HIVandAIDS-adv-unedit.pdf).

- UN Committee on Economic, Social and Cultural Rights, *General Comment No. 17: The right of everyone to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author (art. 15 (1) (c))*, E/C.12/GC/17 (2006). <http://tb.ohchr.org/default.aspx?Symbol=E/C.12/GC/17>.
- UN Committee on the Rights of the Child, *General Comment No. 3: HIV/AIDS and the rights of the child*, CRC/GC/2003 (2003). <http://tb.ohchr.org/default.aspx?Symbol=CRC/GC/2003/3>.
- UN Department of Economic and Social Affairs, *Agreed Conclusions of the Commission on the Status of Women on the Critical Areas of Concern of the Beijing Platform for Action 1996-2009*, Division for the Advancement of Women, ST/ESA/327 (2010). [www.un.org/womenwatch/daw/public/agreedconclusions/Agreed-Conclusions-English.pdf](http://www.un.org/womenwatch/daw/public/agreedconclusions/Agreed-Conclusions-English.pdf).
- UN Economic and Social Council, *The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4 (1984). [www1.umn.edu/humanrts/instreet/siracusaprinciples.html](http://www1.umn.edu/humanrts/instreet/siracusaprinciples.html).
- UN General Assembly.
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  - *Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, A/RES/37/194 (1982). [www.un.org/documents/ga/res/37/a37r194.htm](http://www.un.org/documents/ga/res/37/a37r194.htm).
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  - *Political Declaration on HIV/AIDS*, A/RES/60/262 (June 15, 2006).
  - *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (right to health and informed consent)*, A/64/272 (2009).
  - *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (right to health in the context of access to medicines and intellectual property rights)*, A/HRC/11/12 (2009).
  - *United Nations Rules for the Treatment of Women Prisoners and Non-custodial Measures for Women Offenders [The Bangkok Rules]*, E/2010/16 (2010). [www.un.org/en/ecosoc/docs/2010/res%202010-16.pdf](http://www.un.org/en/ecosoc/docs/2010/res%202010-16.pdf).

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- UN Human Rights Committee, General Comments. [www2.ohchr.org/english/bodies/hrc/comments.htm](http://www2.ohchr.org/english/bodies/hrc/comments.htm).
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## 6. WHAT ARE KEY TERMS RELATED TO TB AND HUMAN RIGHTS?

*A variety of terms is used in TB and human rights work. All definitions are adapted from the WHO unless otherwise indicated.*

### A

#### Active TB

Tuberculosis disease associated with symptoms or signs, including findings on physical examination.

#### Adherence

Active, voluntary and collaborative involvement of the patient in a mutually acceptable course of behavior (including taking the prescribed dose of a particular medicine at the recommended time) to produce the desired therapeutic results.

#### Adherence support

Adherence support refers to medical, social and economic initiatives to help patients who face barriers to accessing TB treatment and care. Examples include providing travel vouchers or transportation to health care facilities, food packages, peer support, education and follow-up, and engaging community health workers to accompany patients as they access health care.<sup>217</sup>

#### Anti-retroviral therapy (ART)

Anti-retroviral drugs inhibit various phases of the life-cycle of the human immunodeficiency virus (HIV), thus reducing HIV-related symptoms and prolonging life expectancy of people living with HIV.

### B

#### BCG (Bacille-Calmette-Guérin) vaccine

A live vaccine against TB derived from an attenuated strain of *Mycobacterium bovis*. The vaccine protects against severe forms of TB in children (TB meningitis and miliary TB), but its efficacy in preventing pulmonary TB in adults is highly variable.

### C

#### Community-based care

Activities conducted outside of formal health facilities (hospitals, health centres and clinics) using community-based structures (such as schools, places of worship and congregate settings, homes). Care is often provided by trained lay and community health workers in patients' homes.

#### Culture

Test to determine whether there are TB bacteria in a person's phlegm or other body fluids. This involves growing organisms on or in media (liquid or solid substances containing nutrients) so that they can be identified. Results can take 2 to 4 weeks in most laboratories.<sup>218</sup>

<sup>217</sup> WHO, *Global Tuberculosis Control 2012* (2012).

<sup>218</sup> CDC, *Core Curriculum on Tuberculosis: What the Clinician Should Know* (2013). [www.cdc.gov/tb/education/corecurr/pdf/corecurr\\_all.pdf](http://www.cdc.gov/tb/education/corecurr/pdf/corecurr_all.pdf).

**D****Directly observed therapy (DOT)**

An adherence-enhancing strategy in which a healthcare worker or other trained person watches a patient swallow each dose of medication and is accountable to the public health system. DOT is the preferred method of care for all patients with TB disease and is a preferred option for patients under treatment for latent infection.<sup>219</sup>

**Drug-resistant TB**

TB disease caused by *Mycobacterium tuberculosis* organisms that are resistant to at least one first-line anti-tuberculosis drug.

**Drug-susceptibility test (DST)**

A laboratory determination to assess whether an *M. tuberculosis* complex isolate is susceptible or resistant to anti-TB drugs that are added to mycobacterial growth medium. The results predict whether a specific drug is likely to be effective in treating TB disease caused by that isolate.<sup>220</sup>

**E****Extensively drug-resistant TB (XDR TB)**

A form of TB caused by bacteria resistant to all the most effective drugs (i.e. MDR-TB plus resistance to any fluoroquinolone and any of the second-line anti-TB injectable drugs: amikacin, kanamycin or capreomycin).

**Extrapulmonary TB**

Patient with tuberculosis of organs other than the lungs (e.g. pleura, lymph nodes, abdomen, genitourinary tract, skin, joints and bones, meninges).

**H****Harm reduction**

Refers to a set of interventions designed to diminish the individual and societal harms associated with drug use, including the risk of HIV infection, without requiring the cessation of drug use. In practice, harm reduction programs include syringe exchange, drug substitution or replacement therapy using substances such as methadone, health and drug education, HIV and sexually transmitted disease screening, psychological counseling, and medical care.

**High burden country**

One of the 22 countries which together account for approximately 80% of all new TB cases arising each year. The WHO also identifies another 27 high MDR-TB burden countries that concentrate more than 85% of MDR-TB cases emerging globally.<sup>221</sup>

**HIV infection**

Infection with the human immunodeficiency virus (HIV) the virus that causes AIDS (acquired immunodeficiency syndrome). A person with both latent TB infection and HIV infection is at very high risk for developing TB disease.<sup>222</sup>

<sup>219</sup> National Tuberculosis Curriculum Consortium (NTCC), "Tuberculosis Glossary". [http://ntcc.ucsd.edu/NTCC\\_glossary.pdf](http://ntcc.ucsd.edu/NTCC_glossary.pdf).

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**I****Infectious TB**

Active TB that is transmissible to others, i.e. contagious, usually determined by a positive sputum smear in case of pulmonary or laryngeal disease.

**Isoniazid or INH**

A medicine used to prevent TB disease in people who have latent TB infection. INH is also one of the four medicines often used to treat TB disease. It is a first-line agent for treatment of all forms of TB.<sup>223</sup>

**Isolation**

A state of separation between persons or groups to prevent the spread of disease. Isolation measures can be undertaken in hospitals or homes, as well as in alternative facilities. Once the diagnosis is made and treatment begun, isolation is usually neither necessary nor appropriate for patients who are willing to undergo treatment. Isolation has a very limited role to play in patients in whom treatment has failed.

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**L****Latent TB infection**

Infection where *M. tuberculosis* bacilli are present in the body but the disease is not clinically active. Not everyone who is infected with tuberculosis bacteria develops the disease. People who are infected may not feel ill and may have no symptoms. The infection can last for a lifetime, but the infected person may never develop the disease itself. People who are infected but who do not develop the disease do not spread the infection to others.

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**M*****Mycobacterium tuberculosis***

The bacterium of the *M. tuberculosis* complex that is the most common causative infectious agent of TB disease in humans. The *M. tuberculosis* complex also includes *M. bovis* and five other related species.

**Multidrug-resistant TB (MDR TB)**

A form of TB that does not respond to the standard six month regimen using first line-drugs (i.e. resistant to isoniazid and rifampicin). It can take two years to treat with drugs that are more toxic, and 100 times more expensive. If the drugs to treat MDR-TB are mismanaged, further resistance can occur.

---

**P****Preventive therapy**

The treatment of subclinical, latent infection with *M. tuberculosis* to prevent progression to active TB disease, usually based on 6–9 months of oral isoniazid.

**Progression**

Development of active tuberculosis disease from a state of latency.

**Pulmonary TB**

Patient with tuberculosis disease involving the lung parenchyma.

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<sup>223</sup> CDC, "TB Terms". [www.cdc.gov/tb/topic/basics/glossary.htm](http://www.cdc.gov/tb/topic/basics/glossary.htm).

**Q****Quarantine**

The detention, isolation or distancing of healthy individuals who may have been exposed to an infectious disease for a given period to slow transmission of the disease.

---

**R****Relapse case**

Patient previously declared cured but with a new episode of bacteriologically positive (sputum smear or culture) TB.

**Rifampin or RIF**

One of the four medicines often used to treat TB disease. It is considered a first-line drug.<sup>224</sup>

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**S****Smear**

Test to determine whether there are TB bacteria in phlegm. To perform this test, lab workers smear the phlegm on a glass slide, stain the slide with a special stain, and look for any TB bacteria on the slide. It usually takes a day to get the results.<sup>225</sup>

**Sputum smear examination**

A laboratory technique in which sputum is smeared on glass slides and stained with an acid-fast stain. Slides are subsequently examined by microscopy for the presence of acid-fast bacilli.

**Sputum**

Phlegm coughed up from deep inside the lungs. Sputum is examined for TB bacteria using a smear; part of the sputum can also be used to do a culture.<sup>226</sup>

**Stop TB Strategy**

The Stop TB Strategy aims to dramatically reduce the global burden of TB by 2015, and has six components: (1) pursue high-quality DOTS expansion and enhancement; (2) address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations; (3) contribute to health system strengthening based on primary health care; (4) engage all care providers; (5) empower people with TB, and communities through partnership; and (6) enable and promote research.

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**T****Tuberculin**

Purified protein derivative (PPD) – a mixture of antigens from a culture filtrate extract of *M. tuberculosis* that is used for skin testing; many of its antigens are non-species specific.

**Tuberculin skin test**

Cutaneous (intradermal) injection of tuberculin to identify people who have been sensitized to mycobacterial antigens by infection with *M. tuberculosis*, non-tuberculous mycobacteria or vaccination with BCG.

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<sup>224</sup> Ibid.

<sup>225</sup> Ibid.

<sup>226</sup> Ibid.

### **Tuberculosis (TB)**

Active disease attributable to *Mycobacterium tuberculosis* complex, typically affecting the lungs and airways in which case it is directly transmissible through droplet.<sup>227</sup> TB spreads rapidly, especially in areas where people are living in crowded conditions, have poor access to health care, and are malnourished. People of all ages can contract tuberculosis. But the risk of developing TB is highest in children younger than three years old, in older people, and people with weakened immune systems (for example, people with HIV).

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### **X**

#### **Xpert MTB/RIF**

A test that employs automated real-time nucleic acid amplification technology for rapid and simultaneous detection of TB and rifampicin resistance.<sup>228</sup>

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<sup>227</sup> TB CARE I, Guidelines to Measure the Prevalence of Active TB Disease Among Health Care Workers, USAID (2012).

<sup>228</sup> Ibid.



# CHAPTER 4



## HARM REDUCTION AND HUMAN RIGHTS

“ Individuals who use drugs do not forfeit their human rights. ”

— Navi Pillay, UN High Commissioner for Human Rights

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# INTRODUCTION

This chapter will introduce you to key issues and resources in harm reduction and human rights, with a particular focus on the rights of people who inject drugs. Some related issues are also addressed in Chapter 2 on HIV, AIDS and Human Rights and Chapter 3 on Tuberculosis and Human Rights.

The chapter is organized into six sections that answer the following questions.

1. How is harm reduction a human rights issue?
2. What are the most relevant international and regional human rights standards related to harm reduction?
3. What is a human rights-based approach to advocacy, litigation, and programming?
4. What are some examples of effective human rights-based work in the area of harm reduction?
5. How can I find additional resources about harm reduction and human rights?
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# I. HOW IS HARM REDUCTION A HUMAN RIGHTS ISSUE?

## What is harm reduction?

There are an estimated 16 million people who inject drugs in over 148 countries around the world.<sup>1</sup> This practice can carry significant health risks, including increased exposure to HIV, hepatitis C and hepatitis B.<sup>2</sup> Yet repressive drug policies and practices create and exacerbate the harms associated with illicit drug use. People who use drugs are regularly harassed and detained, subjected to involuntary and abusive treatment procedures, and denied life-saving medical care. This is true despite evidence that people who use drugs can benefit from many health services even before abstaining from drug use, and that the denial of services makes them and their communities more vulnerable to a range of health and social problems.<sup>3</sup>

“Harm reduction” refers to policies, programs, and practices aimed at reducing drug-related risks and harms by advancing the health and human rights of people who use drugs.<sup>4</sup> As Harm Reduction International notes, “The defining features are the focus on the prevention of harm, rather than on the prevention of drug use itself, and the focus on people who continue to use drugs.”<sup>5</sup> This approach recognizes that “people unable or unwilling to abstain from drug use can still make positive choices to protect their own health in addition to the health of their families and communities.”<sup>6</sup> Harm reduction thus seeks to create an enabling environment for people who use drugs to protect their health and other human rights by providing them with evidence-based information, services, and resources.<sup>7</sup>

While harm reduction refers to an approach, rather than a set of health interventions, the term is commonly applied to a number of measures designed to minimize drug-related risks, particularly in the context of injection drug use. Examples include needle and syringe programs to reduce syringe sharing and reuse; opioid substitution therapy to reduce drug cravings (e.g., methadone and buprenorphine); opioid medications to relieve pain (e.g., morphine); drug-consumption rooms to facilitate access to health care; route-transition interventions to promote non-injecting drug administration; and overdose prevention practices (e.g., naloxone to reverse opioid overdose).<sup>8</sup> Harm reduction measures also encompass broader projects to help people who use drugs access their economic, social, and political rights—including outreach and education programs, provision of legal services, and creation of public policies that are supportive of health.<sup>9</sup>

Harm reduction services are most effective when they meet people who use drugs “where they are,” rather than requiring them to undergo many complicated steps and behavioural changes before they receive help. This is especially true given the range of factors that contribute to drug-related risks and harms, including “the behaviour and choices of individuals, the environment in which they use drugs, and the laws and poli-

1 Mathers B et al, “The global epidemiology of injecting drug use and HIV among people who inject drugs: A systematic review,” *Lancet*, 372, no. 9651 (2008): 1733–1745.

2 Jurgens et al., “People who use drugs, HIV, and human rights,” *Lancet* 376 (2010): 475–485.

3 Harm Reduction International, “What is harm reduction?,” [www.ihra.net/what-is-harm-reduction](http://www.ihra.net/what-is-harm-reduction).

4 Open Society Foundations, “Harm Reduction,” [www.soros.org/topics/harm-reduction](http://www.soros.org/topics/harm-reduction).

5 Harm Reduction International, *What is Harm Reduction?: A position statement from the International Harm Reduction Association* (2010). [www.ihra.net/what-is-harm-reduction](http://www.ihra.net/what-is-harm-reduction).

6 Open Society Foundations, “Harm Reduction,” [www.soros.org/topics/harm-reduction](http://www.soros.org/topics/harm-reduction).

7 Harm Reduction International, *What is Harm Reduction?: A position statement from the International Harm Reduction Association* (2010). [www.ihra.net/what-is-harm-reduction](http://www.ihra.net/what-is-harm-reduction).

8 UN General Assembly, *Report of the Special Rapporteur on the right to health*, A/65/255, para. 50 (Aug. 6, 2010).

9 Rhodes T and Hedrich D, “Chapter 1: Harm reduction and the mainstream in Harm Reduction: Evidence, Impacts and Challenges,” *Harm Reduction: evidence, impacts and challenges* (European Monitoring Centre for Drugs and Drug Addiction, April 2010). [www.emcdda.europa.eu/publications/monographs/harm-reduction](http://www.emcdda.europa.eu/publications/monographs/harm-reduction).

cies designed to control drug use.”<sup>10</sup> For example, while access to treatment for drug dependence is important, not all people who use drugs want or even need such treatment. Access to informal and non-clinical methods of harm reduction is thus equally important. According to Harm Reduction International:

*Harm reduction interventions are facilitative rather than coercive, and are grounded in the needs of individuals.... The objective of harm reduction in a specific context can often be arranged in a hierarchy with the more feasible options at one end (e.g. measures to keep people healthy) and less feasible but desirable options at the other end. Abstinence can be considered a difficult to achieve but desirable option for harm reduction in such a hierarchy. Keeping people who use drugs alive and preventing irreparable damage is regarded as the most urgent priority while it is acknowledged that there may be many other important priorities.*<sup>11</sup>

Harm reduction strategies are therefore complementary to other approaches, including those focused on the reduction of the overall level of drug use in society. According to Anand Grover, the UN Special Rapporteur on the right to the enjoyment of the highest attainable standard of physical and mental health (UN Special Rapporteur on the Right to Health), harm reduction interventions “may operate within restrictive legal regimes.”<sup>12</sup> Nonetheless, it is now recognized that overly restrictive regimes are among the key drivers of drug-related harm. They create risky environments for drug use, drive the problem further underground, and run counter to public health objectives. Harm reduction efforts must therefore include measures to challenge international and national laws and policies that maximize harm.<sup>13</sup> Human rights-based and evidence-based approaches to drug use can assist in this endeavor.

Harm reduction strategies are UN-endorsed and are applied in a range of drug-related health contexts, including injection drugs (such as heroin and other opiates) and non-injection drugs (such as marijuana).<sup>14</sup> They have also been applied to non-drug settings, such as the distribution of condoms to prevent sexually transmitted HIV/AIDS.<sup>15</sup> This chapter will focus primarily on harm reduction aimed at injection drug use. This context offers the largest and most established body of evidence for supporting the development of human rights based programming. However, practitioners working in analogous contexts are encouraged to draw on this chapter for ideas to guide their own work.

## What are the issues and how are they human rights issues?

The current approach to global drug control fuels widespread human rights violations against people who use drugs. In many countries, they are subjected to torture and ill-treatment by police, extrajudicial killings, arbitrary detention, coercive and abusive drug treatment, and denial of essential medicines and basic health services.<sup>16</sup> These abuses are often committed in the name of “medicine, public health or public

<sup>10</sup> Harm Reduction International, *What is Harm Reduction?: A position statement from the International Harm Reduction Association* (2010). [www.ihra.net/what-is-harm-reduction](http://www.ihra.net/what-is-harm-reduction).

<sup>11</sup> Ibid.

<sup>12</sup> UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

<sup>13</sup> Harm Reduction International, *What is Harm Reduction?: A position statement from the International Harm Reduction Association* (2010). [www.ihra.net/what-is-harm-reduction](http://www.ihra.net/what-is-harm-reduction).

<sup>14</sup> Marlatt GA, Larimer, ME, and Witkiewitz, K, eds., *Harm Reduction, Second Edition: Pragmatic Strategies for Managing High-Risk Behaviors* (New York: Guilford Press, 2011).

<sup>15</sup> This approach has been implemented in Thailand, although recent policy developments threaten to jeopardize progress. OSF, *Criminalizing Condoms: How Policing Practices Put Sex Workers and HIV Services at Risk in Kenya, Namibia, Russia, South Africa, the United States, and Zimbabwe* (July 2012). [www.opensocietyfoundations.org/reports/criminalizing-condoms](http://www.opensocietyfoundations.org/reports/criminalizing-condoms). See also Human Rights Watch, *Sex Workers at Risk: Condoms as Evidence of Prostitution in Four US Cities* (2012). [www.hrw.org/reports/2012/07/19/sex-workers-risk](http://www.hrw.org/reports/2012/07/19/sex-workers-risk).

<sup>16</sup> Human Rights Watch, “Drug Policy and Human Rights.” [www.hrw.org/topic/retired-terms/drug-policy-and-human-rights](http://www.hrw.org/topic/retired-terms/drug-policy-and-human-rights). See also Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475–485.



order.”<sup>17</sup> Yet repressive drug laws and policies have not reduced drug use or prevented health-related risks and harms. As the UN Special Rapporteur on the Right to Health states:

*First, people invariably continue using drugs irrespective of criminal laws, even though deterrence of drug use is considered the primary justification for imposition of penal sanctions. Second, drug dependence, as distinct from drug use, is a medical condition requiring appropriate, evidence-based treatment—not criminal sanctions. Finally, punitive drug control regimes increase the harms associated with drug use by directing resources towards inappropriate methods and misguided solutions, while neglecting evidence-based approaches.*<sup>18</sup>

For example, the majority of people who use drugs do not become dependent on drugs and do not require treatment for drug dependence.<sup>19</sup> Even where drug dependence is an issue, it should be treated like any other medical condition—meaning with treatment methods that are voluntary, scientifically and medically appropriate, and of good quality.<sup>20</sup> Finally, people who use drugs are entitled to harm reduction measures as a matter of right under international human rights law.<sup>21</sup> According to Harm Reduction International:

*Human rights apply to everyone. People who use drugs do not forfeit their human rights, including the right to the highest attainable standard of health, to social services, to work, to benefit from scientific progress, to freedom from arbitrary detention and freedom from cruel inhuman and degrading treatment. Harm reduction opposes the deliberate hurts and harms inflicted on people who use drugs in the name of drug control and drug prevention, and promotes responses to drug use that respect and protect fundamental human rights.*<sup>22</sup>

Human rights are relevant to reducing drug-related risks and harms in at least three ways. First, lack of human rights protection creates risky environments for people who use drugs.<sup>23</sup> They are often members of socially and economically marginalized groups to begin with,<sup>24</sup> and their vulnerability is increased by the stigma associated with drug use. Criminalization of drug use and possession often forces people who use drugs to adopt risky injection practices that increase the risk of poor health and illness, such as reused or shared needles, hurried injection to avoid detection, or improper disposal of syringes.<sup>25</sup>

17 Open Society Foundations, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (March 2009). [www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field](http://www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field).

18 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255, para. 15 (Aug. 6, 2010).

19 Ibid.

20 Open Society Foundations, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (2009).

21 Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475–485; UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

22 Harm Reduction International, *What is Harm Reduction?: A position statement from the International Harm Reduction Association* (2010). [www.ihra.net/what-is-harm-reduction](http://www.ihra.net/what-is-harm-reduction).

23 Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475–485.

24 United Nations Office on Drugs and Crime (UNODC). [www.unodc.org/](http://www.unodc.org/).

25 Global Commission on HIV and the Law, *HIV and the Law: Risks, Rights and Health* (2012). [www.hivlawcommission.org/index.php/report](http://www.hivlawcommission.org/index.php/report).

Second, lack of human rights protection prevents people who use drugs from accessing services and treatment. In many countries, repressive drug laws and policies have “reinforced the status of people who use drugs as social outcasts, driving drug use underground, compromising the HIV/AIDS response, as well as discouraging people who use drugs from accessing treatment.”<sup>26</sup> People who use drugs may refrain from seeking assistance for drug use or drug-related health issues in order to avoid discrimination, violations of their privacy, arrest, imprisonment, and involuntary treatment.<sup>27</sup>

Third, lack of human rights protection in the context of drug use disproportionately impacts members of vulnerable and marginalized communities. In the United States, African-Americans are arrested at higher rates than white Americans for comparable offenses and more than 80% of drug-related arrests are for drug possession rather than sales. The UN Special Rapporteur on the Right to Health notes: “Accumulation of such minor offences can lead to incarceration and further marginalization of these already vulnerable individuals, increasing their health-related risks.”<sup>28</sup> The social vulnerability of drug users is demonstrated by the fact that in some countries, they are confined with other “social outcasts”—including people with mental disabilities, sex workers, and the homeless.<sup>29</sup>

The following are some examples of key human rights issues related to people who use drugs, denial of harm reduction services, and human rights.

### Criminalization of drug use and possession

Around the world, criminalization of drug use and possession “creates more harm than the harms it seeks to prevent.” Repressive drug laws and policies disproportionately punish people who use drugs compared to those who sell or produce drugs. They also perpetuate stigma, risky forms of drug use, and negative health and social consequence—not only for those who use drugs, but the wider community as well.<sup>30</sup> The Vienna Declaration, adopted at the 2010 International AIDS Conference, recognizes that the criminalization of drug use directly fuels the global HIV epidemic.<sup>31</sup> The UN Special Rapporteur on the Right to Health confirms that criminalization runs counter to public health aims:

*Higher rates of legal repression have been associated with higher HIV prevalence among people who use injecting drugs, without a decrease in prevalence of injecting drug use. This is a likely result of individuals’ adopting riskier injection practices such as sharing of syringes and injection supplies, hurried injecting, or use of drugs in unsafe places (such as needle-shooting galleries) out of fear of arrest or punishment.*<sup>32</sup>

As a result, around one in ten new HIV infections result from injection drug use and up to 90% of all infections occur in people who inject drugs in regions such as Eastern Europe and Central Asia. In many of the same countries, harm reduction services are not only unavailable but prohibited by law, further increasing the risk of HIV transmission.<sup>33</sup>

26 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255, (Aug. 6, 2010).

27 Open Society Institute and International Harm Reduction Development, *Protecting the Human Rights of Injection Drug Users: The Impact of HIV and AIDS* (2005). [www.opensocietyfoundations.org/publications/protecting-human-rights-injection-drug-users-impact-hiv-and-aids](http://www.opensocietyfoundations.org/publications/protecting-human-rights-injection-drug-users-impact-hiv-and-aids).

28 Ibid.

29 Open Society Foundations, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (2009).

30 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

31 International Center for Science in Drug Policy, *The Vienna Declaration* (2010). [www.viennadeclaration.com](http://www.viennadeclaration.com).

32 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

33 Ibid. See also: Global Commission on HIV and the Law, *HIV and the Law: Risks, Rights and Health* (2012). [www.hivlawcommission.org/index.php/report](http://www.hivlawcommission.org/index.php/report).

The harshness of drug laws and law enforcement practices varies considerably by jurisdiction.<sup>34</sup> In many countries, people are arrested and detained for using drugs “on the basis of mere police suspicion or a single positive urine test” and may be remanded to treatment centers “for months or years without medical assessment or right of appeal.”<sup>35</sup> In other countries, including several members of the Commonwealth of Independent States, drug use may not be prohibited per se, but possession of drug paraphernalia, including unused syringes to prevent HIV, can be cause for arrest. Additionally, individuals can be subjected to prolonged imprisonment if they are found with “large” or “extra-large” quantities of illicit drugs—in some countries, defined as the residue in a used syringe or half a cigarette of cannabis.<sup>36</sup>

At the extreme end, more than 30 UN member states retain the death penalty for drug offenses,<sup>37</sup> despite clear guidance from human rights authorities that the death penalty must be reserved for the most serious crimes, and that drug-related offenses do not meet those criteria.<sup>38</sup> For example, in 2003, “the Thai government’s efforts to make the country ‘drug free’ led to the extrajudicial killing of some 2800 people.”<sup>39</sup> People have also been executed for drug offenses in China, Iran, Saudi Arabia, Vietnam, Singapore, and Malaysia, although Singapore and Malaysia have limited enforcement in recent years and China and Vietnam are reviewing their legislation. The International Harm Reduction Association notes:

*Retentionist governments sometimes justify harsh sentences for drugs as a necessary deterrent to social risks linked to drug use—such as addiction, overdose and blood-borne infections usually associated with drugs like heroin, cocaine and amphetamine-type stimulants. Yet the reality is more nuanced. Many of the people sentenced to die are not traders in so-called ‘hard’ drugs and instead are subject to the death penalty for trafficking in marijuana or hashish.*<sup>40</sup>

Moreover, drug users can also be charged with trafficking, particularly in countries with weak rule of law. Jurgens et al. note, “The amount of illicit drugs possessed, produced, or sold to constitute a capital crime varies from 2 grams to 25 kilograms, indicating an arbitrariness that defies human rights norms on the death penalty.”<sup>41</sup>

Criminalization of drug use is implicated in the violation of many human rights, including the right to life, to health, to bodily integrity, to due process, to freedom from arbitrary arrest, and to freedom from torture and cruel, inhuman, and degrading treatment.<sup>42</sup> While the 1984 Siracusa Principles on the Limitation and Derogation of Principles in the International Covenant on Civil and Political Rights permit restrictions on individual liberties in limited circumstances, they must be “sanctioned by law, serve a legitimate public health goal... necessary to achieve that goal... no more intrusive or restrictive than necessary, and ... non-discriminatory in application.”<sup>43</sup> The criminal penalties imposed against people who use drugs lack an evidence basis in public health and fall short of these stringent requirements.

34 Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475–485.

35 Open Society Foundations, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (2009). <http://www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field>.

36 Alternative Georgia, *Reforming Drug Policy for HIV/AIDS Prevention* (2005).

37 Harm Reduction International, *The Death Penalty for Drug Offenses: Global Overview* (2011). [www.ihra.net/contents/1080](http://www.ihra.net/contents/1080).

38 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

39 Human Rights Watch, “Drug Policy and Human Rights.” <http://www.hrw.org/node/82339>.

40 Harm Reduction International, *The Death Penalty for Drug Offenses: Global Overview* (2011). [www.ihra.net/contents/1080](http://www.ihra.net/contents/1080).

41 Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475–485.

42 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

43 Amon J., *Preventing the Further Spread of HIV/AIDS: The Essential Role of Human Rights* (Human Rights Watch). [www.old.msmgf.org/documents/NorthAmerica/TakeAction/PreventingtheFurtherSpreadofHIVAIDSTheEssentialRoleofHumanRights.pdf](http://www.old.msmgf.org/documents/NorthAmerica/TakeAction/PreventingtheFurtherSpreadofHIVAIDSTheEssentialRoleofHumanRights.pdf).

## Incarceration and denial of services in prisons

Due to harsh and repressive drug control regimes, people who use drugs but who do no harm enter the criminal justice system in large numbers. Jurgens et al. note:

*The incarceration of many drug-dependent people—often for lengthy periods of time and for minor offences such as possession of very small amounts of drugs—also raises human rights and health concerns. In many countries, a substantial proportion of prisoners are drug dependent. For people who inject drugs, imprisonment is a common event, with reported incarceration rates of 56–90% in this population.<sup>44</sup>*

Once in prison, they are often exposed to conditions that further jeopardize their rights, including unsanitary facilities, overcrowding, inadequate food, violence, sexual assault, and inadequate medical attention.<sup>45</sup> HIV, hepatitis B and C, and tuberculosis are especially prevalent in prison settings given high rates of injection drug use, risky injecting practices, and lack of prevention and treatment services.<sup>46</sup> Access to sterile injection equipment, the single most important determinant of HIV infection, remains poor, as does access to antiretroviral therapy.<sup>47</sup> The UN Special Rapporteur on the Right to Health notes that these factors “create enormous risk for inmates [which] is then passed on to members of the public upon prisoners’ release.”<sup>48</sup>

Many prisons also fail to provide medically appropriate care and medications, including treatment for drug dependence. For example, substitution therapy, considered the standard of care for opiate addictions, is rarely available, leaving many people alone to face withdrawal without medical support. In New York, many prisoners are denied such services “as part of the disciplinary sanction.”<sup>49</sup> At the same time, prisons often deny people who use drugs the right to give informed consent before undergoing medical procedures, including mandatory HIV testing, or deny them the opportunity to refuse treatment, including for drug dependence. These practices constitute a breach of medical ethics and a violation of international human rights law.<sup>50</sup>

## Extrajudicial detention, abuse, and compulsory treatment

Even when governments profess to treat people who use drugs as patients rather than criminals, the result is frequently harsh, punitive regimes with no medical or public health benefit. Many countries use compulsory detention as a form of “treatment,” and people suspected of using drugs are regularly confined for months or years without a trial or even an evaluation of their drug dependency.<sup>51</sup> As Clark et al. note, these so-called compulsory treatment centers “are probably more aptly named ‘extrajudicial drug detention centres.’”<sup>52</sup> They typically fall outside the criminal justice system, are run by police, military, or security personnel, and lack judicial oversight, government regulation, and medical supervision.<sup>53</sup>

44 Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475–485.

45 UNODC, “Sustainable livelihoods.” [www.unodc.org/eastasiaandpacific/en/topics/sustainable-livelihoods/index.html](http://www.unodc.org/eastasiaandpacific/en/topics/sustainable-livelihoods/index.html).

46 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

47 Jurgens et al., “People who use drugs, HIV, and human rights”, *Lancet* 376 (2010): 475–485.

48 Open Society Institute and International Harm Reduction Development, *Protecting the Human Rights of Injection Drug Users: The Impact of HIV and AIDS* (2005). <http://www.opensocietyfoundations.org/publications/protecting-human-rights-injection-drug-users-impact-hiv-and-aids>.

49 Human Rights Watch, “Drug Policy and Human Rights.” <http://www.hrw.org/node/82339>.

50 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

51 Open Society Foundations, *Treated with Cruelty: Abuses in the Name of Rehabilitation* (2011). [www.opensocietyfoundations.org/publications/treated-cruelty-abuses-name-rehabilitation](http://www.opensocietyfoundations.org/publications/treated-cruelty-abuses-name-rehabilitation).

52 Clark et al, *Voluntary treatment, not detention, in the management of opioid dependence* (WHO, 2013). [www.who.int/bulletin/volumes/91/2/13-117184/en/index.html](http://www.who.int/bulletin/volumes/91/2/13-117184/en/index.html).

53 Open Society Foundations, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (2009). [www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field](http://www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field).

People remanded to these facilities for drug treatment rarely receive effective, medically necessary therapies based on scientific evidence and offered under conditions of informed consent. Instead, they are frequently subjected to egregious violations of their human rights, in some cases rising to the level of torture. The Open Society Institute's International Harm Reduction Development Program (IHRD) notes:

*What is referred to as 'treatment' in many centers in fact includes painful, unmedicated withdrawal, beatings, military drills, verbal abuse, and sometimes scientific experimentation without informed consent. Forced labor, without pay or at extremely low wages, at times in total silence, is used as 'rehabilitation,' with detainees punished if work quotas are not met.*<sup>54</sup>

IHRD has documented numerous examples of patients forced to undergo perverse, punitive, and abusive treatment:

- “Former detainees in Cambodia report being locked in cement facilities where they are forced to withdraw ‘cold turkey,’ and not allowed to use the toilet despite the diarrhea that is commonly associated with such withdrawal, subjected to sexual violence and beatings with batons and boards, and compelled to confess to unsolved criminal cases.”
- In South Africa, “[Former residents of one center report being kicked and beaten if they did not maintain sufficient speed during physical training, which consisted of carrying boulders on their bare backs, rolling long distances on hot pavement, or running while carrying as much as 25 liters of water and then being forced to drink it all, pausing only to vomit.”
- “In Nagaland, India, drug users have been crammed into thorn-tree cages in a sitting position. In Punjab, drug treatment patients are routinely tortured, and in some cases have been beaten to death.”<sup>55</sup>
- Moreover, people may be forced to undergo dangerous and experimental therapy, a clear violation of their right to be free from “torture, nonconsensual medical treatment and experimentation.” IHRD has documented:<sup>56</sup>
- In China, “Private and voluntary treatment methods include partial lobotomy through the insertion of heated needles clamped in place for up to a week to destroy brain tissue thought to be connected to cravings.”
- “Throughout Eastern Europe and Central Asia... patients have ampoules or substances injected under the skin and are told that they will explode and poison them if they drink or use drugs.”<sup>57</sup>

Beyond this so-called treatment, people detained in these centers are frequently denied access to basic medical treatment and care, including evidence-based treatment for drug dependence, medical care for HIV and other health conditions, and access to HIV prevention measures. As the UN Special Rapporteur on the Right to Health notes, “Imposition of compulsory treatment, at the expense of OST and other harm reduction interventions, also increases the risk of disease transmission, particularly HIV/AIDS.” This constitutes a further violation of the right to health.

54 Open Society Foundations, *Treatment or Torture?: Applying International Human Rights Standards to Drug Detention Centers* (2011). [www.opensocietyfoundations.org/sites/default/files/treatment-or-torture-20110624.pdf](http://www.opensocietyfoundations.org/sites/default/files/treatment-or-torture-20110624.pdf).

55 Open Society Foundations, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (2009). [www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field](http://www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field).

56 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

57 Open Society Foundations, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (2009). [www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field](http://www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field).

While the heads of 12 UN agencies have signed a statement calling for an end to detention as treatment, the practice continues.<sup>58</sup> For example, there are an estimated 300,000 to 500,000 people undergoing compulsory drug detention in China, and as many 60,000 people each year in Vietnam. Thousands more are interned in Cambodia, Thailand, Malaysia, Laos, Burma, and other countries in Asia.<sup>59</sup> Conditions in drug detention centers are so severe that people who use drugs are sometimes forced to resort to desperate measures. In one Chinese study, up to 10% had swallowed nails or glass to avoid such detention.<sup>60</sup>

For legal assessments detailing the violations of international human rights law represented by these practices, please consult the following Open Society Foundation resources: *Treatment or Torture? Applying International Human Rights Standards to Drug Detention Centers* (2011); *Treated with Cruelty: Abuses in the Name of Rehabilitation* (2011); and *Human Rights Abuses in the Name of Drug Treatment: Reports From the Field* (2009).

## Police harassment, ill treatment, and torture

Criminalization of drug use is common, creating tension between law enforcement and harm reduction efforts.<sup>61</sup> Persons who use drugs, already a marginalized group in society, are vulnerable to a range of human rights abuses by police and law enforcement officers. Police often target them in order to meet arrest quotas.<sup>62</sup> According to Human Rights Watch:

*People who use drugs are routinely subjected to violence during arrest and detention, in some cases to extract confessions. Law enforcement in many countries has relied on tactics amounting to inhuman treatment or in some cases to torture, including forcing suspects to suffer withdrawal to extract confessions and extorting money from them.*

In some countries, such as Russia, Georgia, Ukraine, and Thailand, people who use drugs are identified and listed in registries that “brand [them] as sick and dangerous, sometimes for life” and fuel violations of their civil rights, including increased police surveillance and discrimination in employment, travel, immigration, and child custody.<sup>63</sup>

Police harassment and abuse directly contribute to drug-related harms and undermine important public health objectives, violating the right to health of people who use drugs and the communities in which they live. The UN Special Rapporteur on the Right to Health notes:

*Police crackdowns and other interventions associated with criminalization of drug use and possession also result in displacement of drug users from areas serviced by harm-reduction programmes, decreasing their ability to participate in needle and syringe programmes, opioid substitution therapy (OST) and access to outreach workers. Access to emergency assistance in the instance of an overdose also is impeded, and the incidence of overdose may be increased by disrupting access to regu-*

58 United Nations, *Joint Statement: Compulsory Drug Detention and Rehabilitation Centres* (2012). [www.unaids.org/en/media/unaids/contentassets/documents/document/2012/JC2310\\_Joint%20Statement6March12FINAL\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/JC2310_Joint%20Statement6March12FINAL_en.pdf); Human Rights Watch, *Torture in the Name of Treatment* (2012). [www.hrw.org/sites/default/files/reports/HHR%20Drug%20Detention%20Brochure\\_LOWRES.pdf](http://www.hrw.org/sites/default/files/reports/HHR%20Drug%20Detention%20Brochure_LOWRES.pdf).

59 Open Society Foundations, *Treatment or Torture?: Applying International Human Rights Standards to Drug Detention Centers* (2011). [www.opensocietyfoundations.org/sites/default/files/treatment-or-torture-20110624.pdf](http://www.opensocietyfoundations.org/sites/default/files/treatment-or-torture-20110624.pdf).

60 Wolfe D, “Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union,” *International Journal of Drug Policy* (2007).

61 Stevens A, Stöver H and Brentari C, “Chapter 14: Criminal justice approaches to harm reduction in Europe in Harm Reduction: evidence, impacts and challenges,” *Harm Reduction: evidence, impacts and challenges* (European Monitoring Centre for Drugs and Drug Addiction, April 2010). [www.emcdda.europa.eu/publications/monographs/harm-reduction](http://www.emcdda.europa.eu/publications/monographs/harm-reduction).

62 Global Commission on HIV and the Law, *HIV and the Law: Risks, Rights and Health* (2012). [www.hivlawcommission.org/index.php/report](http://www.hivlawcommission.org/index.php/report).

63 Ibid. Open Society Institute, *Human Rights Abuses in the Name of Drug Treatment: Reports from the Field* (2009). [www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field](http://www.opensocietyfoundations.org/publications/human-rights-abuses-name-drug-treatment-reports-field).



*lar injecting networks and drug suppliers.... Any efforts to decriminalize or de-penalize drug use or possession must be coupled with appropriate strategies to ensure that the fear and stigma that were reinforced through excessive policing are ameliorated.<sup>64</sup>*

## Denial of evidence-based treatment and care, including harm reduction

People who inject drugs experience heightened risk of HIV, hepatitis B<sup>65</sup> and C,<sup>66</sup> and TB.<sup>67</sup> Yet in many countries, harm reduction services are underutilized or even proscribed. The UN Special Rapporteur notes:

*Currently, 93 countries and territories support a harm reduction approach. As of 2009, needle and syringe programmes had been implemented in 82 countries, and OST in 70 countries, with both interventions available in 66 countries. However, needle and syringe programmes have been confirmed to be absent in 55 countries where injecting drugs are used, and OST in 66 such countries. It is particularly disturbing that OST is unavailable in 29 countries throughout Africa and the Middle East, especially in the light of the HIV burden throughout Africa.<sup>68</sup>*

Even where harm reduction measures are legal, people may refrain from seeking assistance for drug use or drug-related health issues in order to avoid discrimination, violations of their privacy or even incarceration.<sup>69</sup> Human Rights Watch notes:

*In some countries, many people who inject drugs do not carry sterile syringes or other injecting equipment, even though it is legal to do so, because possession of such equipment can mark an individual as a drug user and expose him or her to punishment on other grounds. Police presence at or near government sanctioned harm reduction programs (such as legal needle exchange sites) drives drug users away from these services out of fear of arrest or other punishment.<sup>70</sup>*

The illegal status of drug use and possession also shape the quality and type of treatment people who use drugs receive. People who use drugs are often discriminated against in medical settings and may be denied access to antiretroviral therapy and other medical treatments.<sup>71</sup> For example, it is estimated that only 4% of people who inject drugs with HIV are receiving antiretroviral treatment.<sup>72</sup> People who use drugs also face disproportionate barriers in accessing housing other social services.

## Denial of access to controlled medicines

An essential aspect of reducing drug-related harms is increasing access to controlled essential medicines for therapeutic purposes, including pain, drug dependence, and other health conditions. According to the UN Special Rapporteur on the Right to Health:

64 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

65 World Health Organization (WHO), *Guidance on Prevention of viral Hepatitis B and C among people who inject drug*, Policy Brief (July 2012). [http://apps.who.int/iris/bitstream/10665/75192/1/WHO\\_HIV\\_2012.18\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75192/1/WHO_HIV_2012.18_eng.pdf).

66 Ibid.

67 Harm Reduction International, *Global State of Harm Reduction 2012* (2012). [www.ihra.net/global-state-of-harm-reduction-2012](http://www.ihra.net/global-state-of-harm-reduction-2012).

68 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255, para. 15 (Aug. 6, 2010).

69 Open Society Institute and International Harm Reduction Development, *Protecting the Human Rights of Injection Drug Users: The Impact of HIV and AIDS* (2005). [www.opensocietyfoundations.org/publications/protecting-human-rights-injection-drug-users-impact-hiv-and-aids](http://www.opensocietyfoundations.org/publications/protecting-human-rights-injection-drug-users-impact-hiv-and-aids).

70 Human Rights Watch, "Drug Policy and Human Rights." <http://www.hrw.org/node/82339>.

71 Jurgens et al., "People who use drugs, HIV, and human rights", *Lancet* 376 (2010): 475–485.

72 Harm Reduction International, *Global State of Harm Reduction 2012* (2012). [www.ihra.net/global-state-of-harm-reduction-2012](http://www.ihra.net/global-state-of-harm-reduction-2012); Mathers BM et al, "The global epidemiology of injecting drug use and HIV among people who inject drugs: A systematic review," *Lancet* 372, no. 9651 (2010): 1733–1745.



*These medications are often restricted excessively for fear they will be diverted from legitimate medical uses to illicit purposes. Although preventing drug diversion is important, this risk must be balanced against the needs of the patient to be treated.... Where patients with HIV are also dependent on drugs, they may be denied access to both OST and palliative care.... Restrictive laws are a particular problem in the cases of methadone and buprenorphine, drugs used for OST. In some States use of these drugs is outlawed.<sup>73</sup>*

Access to essential medicines is a minimum core obligation of the right to health and the failure of states to provide people who use drugs access controlled medicines constitutes a violation of this right.

## **Vulnerability of women, children and young people who use drugs<sup>74</sup>**

Young people frequently represent a significant proportion of people who inject drugs; in some countries, injection drug use starts as early as age 12. In one study of harm reduction programs in Georgia, 16.8% of the respondents were under 25. In another study in Romania, 16% of the participants were aged 15–19 and 45% were aged 20–24. Based on these and similar findings across Central and Eastern Europe, UNAIDS estimates that around 45% of all new HIV infections are among young people under age 25.

There is also a high prevalence of injection drug use among women in many parts of the world. According to Harm Reduction International, “Though precise data on women who use drugs are rarely available, women have been estimated to represent about 40% of drug users in the United States and some parts of Europe, 20% in Eastern Europe, Central Asia, and Latin America, between 17-40% in various provinces of China, and 10% in some other Asian countries.” Advocates also note an overlap between commercial sex work and injecting drug use in some areas, which contributes to increased risk of drug-related harms.<sup>75</sup>

## **What are current interventions and practices in the area of harm reduction?**

Harm reduction measures include a range of interventions to address the medical and ethical problems outlined above. Some target biomedical issues while others target the social determinants of health – either root causes or the larger environment in which people access their right to health. Harm reduction measures can be tailored to take specific vulnerability factors into account, such as age, gender or incarceration, and they can be used in combination.

Additionally, some of these measures include a human rights component and are explicitly designed to respect and protect the dignity and rights of people who use drugs. The following list includes both rights-based and public health-based interventions, as well as other approaches to ensuring the respect of the rights of people who inject drugs that may not be traditionally characterized as harm reduction.

<sup>73</sup> UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255, para. 15 (Aug. 6, 2010).

<sup>74</sup> Harm Reduction International, *Global State of Harm Reduction 2012* (2012). [www.ihra.net/global-state-of-harm-reduction-2012](http://www.ihra.net/global-state-of-harm-reduction-2012).

<sup>75</sup> Harm Reduction International, *Harm Reduction and Human Rights: The Global Response to Drug-Related HIV Epidemics* (2009). [www.ihra.net/files/2010/06/01/GlobalResponseDrugRelatedHIV\(2\).pdf](http://www.ihra.net/files/2010/06/01/GlobalResponseDrugRelatedHIV(2).pdf).

### Needle and syringe programs

These programs are designed to provide sterile injection equipment to people who inject drugs and have been extensively proven to prevent and control HIV and other blood-borne infections.<sup>76</sup> Programs differ greatly from fixed and mobile sites, community outreach, pharmacy provision, and vending machines.

### Supervised injection facilities and drug-consumption rooms

Medically supervised injection facilities provide a hygienic site for injection drug use. The sites often provide sterile injection equipment, as well as information about drugs and medical and treatment referrals. Some sites may offer additional medical or counselling services.

The Special Rapporteur on the Right to Health stated that the “potential benefits of drug-consumption rooms include prevention of disease transmission and reduced venous damage, as well as encouraging entry to treatment and other services. Evidence exists that drug consumption rooms have contributed to reductions in overdose rates, and increased access to medical and social services.”<sup>77</sup>

### Route-transition interventions

Route transition interventions strive to prevent transitions to more harmful methods of drug administration or attempt to change a drug users current method of drug administration to a safer method. An example would be promoting smoking heroin rather than injecting heroin.

### Opioid substitution therapy

Opioid substitution therapy (OST) is the prescription of opioid medicines to persons with opioid dependence under medical supervision. This is also known as substitution or replacement therapy, drug dependence treatment, or prescription of substitute medications. OST facilitates the reduction or discontinuation of drug injection and increases the normalization of the patient’s lifestyle. OST also reduces risk of contracting blood-borne disease and increases the possibility of treatment if the patient is already a carrier, and reduces overdose mortality. Traditional opioid substitutions are methadone and buprenorphine, but some countries also use slow-release morphine or codeine. Heroin-assisted treatment (HAT) is an effective option for people who continue using intravenous heroin while on methadone maintenance or who are not enrolled in treatment.<sup>78</sup>

### Overdose prevention

Overdose prevention practices can be promoted through education and outreach and overdose interventions can be as simple as first-aid training. Administration of the drug Naloxone, “an opioid receptor antagonist used to reverse depression of the central nervous system in cases of opioid overdose,” is also crucial for minimizing overdose risk, but it must be available for distribution and administration.<sup>79</sup>

76 WHO, UNAIDS and UNODC, *Guide to Starting and Managing Needle and Syringe Programmes* (2007). [www.who.int/hiv/pub/idu/needleprogram/en/index.html](http://www.who.int/hiv/pub/idu/needleprogram/en/index.html); World Health Organization, *Effectiveness of sterile needle and syringe programming in reducing HIV/AIDS among injecting drug users* (2004). <http://whqlibdoc.who.int/publications/2004/9241591641.pdf>; S. Burris et al, “Physician Prescribing of Sterile Injection Equipment to Prevent HIV Infection: Time for Action,” *Annals of Internal Medicine* 133, no. 3 (2000): 219.

77 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255, (Aug. 6, 2010).

78 See, e.g., Haasen C et al. “Heroin-assisted treatment for Opioid Dependence: Randomised Controlled Trial”, *The British Journal of Psychiatry* 191:55-62 (2007). <http://bjp.rcpsych.org/content/191/1/55>.

79 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health*, A/65/255, (Aug. 6, 2010).

### Outreach and education programs

Education and outreach programs can involve assistance with access to services, peer mentoring or counselling, support groups, provision of sterile injection equipment, or provision of educational materials on harm reduction, safe drug use, or safe sex.

### Access to justice through legal aid, paralegal training, and legal empowerment <sup>80</sup>

Evidence suggests that access to legal aid, paralegal services, and legal empowerment can greatly enhance the health of drug users. Legal services can include assistance with access to housing, health, and social services; training and supporting non-lawyers as paralegals and companions; training drug users to know and assert their rights; documenting human rights abuses against drug users and related advocacy; and ensuring the legality of health services for drug users.

### Access to medical services

#### *Access to medical services*

People who inject drugs are deterred from accessing available services for a variety of reasons. Harm reduction programs should ensure that people who inject drugs are afforded access to medical services without discrimination or judgment.

#### *Access to HIV treatment*

Evidence has shown that persons who inject drugs can, with proper supports, enjoy the same benefits from ART as other people with HIV. However, as mentioned above, people who inject drugs account for a large number of HIV infections, but a small fraction of those with access to antiretroviral treatment (ART).

#### *Vaccination, diagnosis, and treatment of hepatitis B and C*

WHO recommends countries provide catch-up vaccination against hepatitis B for people at increased risk (there is no vaccine against hepatitis C).<sup>81</sup> WHO also recommends that people who inject drugs receive the rapid hepatitis B vaccination regimen as well as incentives to complete the regimen. People who inject drugs should also have access to medical services to ensure treatment of hepatitis.

#### *Integrated services*

Treatment for HIV and/or TB can be integrated with OST to more adequately address the needs of people who inject drugs. For example, if TB treatment requires hospital stays, people who inject drugs may avoid treatment to also avoid withdrawal symptoms. Models on integrated services have been developed over the past few years, resulting in more information on best practices.<sup>82</sup>

<sup>80</sup> Csete J and Cohen J, "Health Benefits of Legal Services for Criminalized Populations: The Case of People Who Use Drugs, Sex Workers, and Sexual and Gender Minorities," *Journal of Law, Medicine, and Ethics* (Winter 2010).

<sup>81</sup> World Health Organization, *Four ways to reduce hepatitis infections in people who inject drugs* (July 2012). [http://www.who.int/mediacentre/news/notes/2012/hiv\\_hepatitis\\_20120721/en/](http://www.who.int/mediacentre/news/notes/2012/hiv_hepatitis_20120721/en/).

<sup>82</sup> WHO, UNAIDS and UNODC, *Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users: An Integrated Approach* (2008). [http://whqlibdoc.who.int/publications/2008/9789241596930\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241596930_eng.pdf).

### Decriminalization

Harm reduction advocates have always sought to decriminalize harm reduction services and to decriminalize drug users. On July 11, 2012, the UN assembled Commission on HIV and the Law publicly called for the decriminalization of drug use, needles, and the personal possession of drugs.<sup>83</sup> In June 2012, the Global Commission on Drug Policy also released a report recommending the decriminalization of drug use.<sup>84</sup> It should also be noted that harm reduction challenges laws and policies that may generate or exacerbate harm. “In many countries, harm reduction is further hampered by criminal laws, disproportionate penalties and law enforcement.”<sup>85</sup>

### Elimination of the death penalty

The death penalty is one of the most egregious examples of the punitive laws, policies, and measures that operate on the situation of people who inject drugs. The death penalty can be imposed for certain drug offenses, including drug trafficking. Oftentimes people who use drugs can be charged with trafficking, particularly in countries with weak rule of law. The UN Human Rights Committee has found that drug offenses are not serious crimes, and therefore the death penalty is not permitted under international human rights law for drug offenses.

### Protection against abuses by police and health care providers

Mistreatment of people who use drugs by police and healthcare providers is widespread. Police use the threat of incarceration or painful withdrawal symptoms to coerce testimony and extort money from people who use drugs. In many countries, police or health care providers release confidential information regarding HIV or drug-using status, register drug users’ names on government lists, and deny them employment or services. It is common for governments to impose lengthy prison sentences for minor drug offenses. This not only constitutes cruel and unusual punishment, but also catalyzes HIV transmission, since hundreds of thousands of people are incarcerated in environments where drug injection and unprotected sex continue, and where HIV treatment and prevention measures are often unavailable.

### Support for political participation

More than two decades of experience with HIV have shown that “hard-to-reach” populations are their own best advocates. Despite the importance of involving those who are directly affected in the formation of drug and harm reduction policy, drug users have often been excluded, even from those mechanisms that are intended to increase participation of drug users.

Women often wait longer to seek diagnosis and treatment for TB. This in turn can “increase the severity of their illness, decrease the success of treatment, and raise the risks that they will infect others.”<sup>86</sup> Where TB treatment is provided mostly via in-patients modes—the norm in many former Soviet countries—women may face particular difficulty adhering to treatment due to their child care responsibilities or inability to leave home for extended periods. While men and women may both face economic consequences related TB stigma, women can also face lost marriage prospects, divorce, desertion and separation from their children.<sup>87</sup>

83 Wolfe D and Csete J, *Decriminalization of Drugs as HIV Prevention* (July 2012). [www.opensocietyfoundations.org/voices/decriminalization-drugs-hiv-prevention](http://www.opensocietyfoundations.org/voices/decriminalization-drugs-hiv-prevention); Global Commission on HIV and the Law, *HIV and the Law: Rights and Health* (July 2012). [www.hivlawcommission.org/](http://www.hivlawcommission.org/).

84 Global Commission on Drug Policy, *The War on Drugs and HIV/AIDS: How the Criminalization of Drug Use Fuels the Global Pandemic* (June 2012). [http://globalcommissionondrugs.org/wp-content/themes/gcdp\\_v1/pdf/GCDP\\_HIV-AIDS\\_2012\\_REFERENCE.pdf](http://globalcommissionondrugs.org/wp-content/themes/gcdp_v1/pdf/GCDP_HIV-AIDS_2012_REFERENCE.pdf).

85 Human Rights Watch, OSI: Public Health Program, Canadian HIV/AIDS Legal Network, and Harm Reduction International, *Human Rights and Drug Policy: Harm Reduction* (2010).

86 TB Alert, “TB and Women: TB is the single biggest killer of young women.” [www.tbalert.org/worldwide/TBAndwomen.php](http://www.tbalert.org/worldwide/TBAndwomen.php).

87 Courtwright A and Turner AN, “Tuberculosis and Stigmatization: Pathways and Interventions,” *Public Health Reports* 125, Suppl 4 (2010):34-42; Somma D et al., “Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia,” *International Journal of Tuberculosis and Lung Disease* 17, no. 7 (2008): 856-866. [www.who.int/tdr/publications/documents/tb-related-stigma.pdf](http://www.who.int/tdr/publications/documents/tb-related-stigma.pdf).

## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO HARM REDUCTION?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to harm reduction. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<p><b>UN treaty body interpretation</b></p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
<b>Human rights standards</b>	<p><b>Case law</b></p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court’s jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and harm reduction.

## Abbreviations

In the tables, we use the following abbreviations to refer to the twelve treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment ( <b>CAT</b> )	Committee against Torture ( <b>CAT Committee</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Life	Art. 3	Art. 6(1)				Art. 6(1)
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)
Arbitrary Arrest and Detention	Art. 9	Art. 9				Art. 37(b)
Fair Trial	Art. 8, Art. 10, Art. 11	Art. 9, Art. 14, Art. 15			Art. 5(a), Art. 6	Art. 40
Privacy	Art. 12	Art. 17				Art. 16
Expression and Information	Art. 19	Art. 19(2)			Art. 5(d) (viii)	Art. 12, Art. 13, Art. 17
Assembly and Association	Art. 20	Art. 21, Art. 22			Art. 5(d) (ix)	Art. 15
Bodily Integrity						
Non-discrimination and Equality	Art. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24
Women and Children	Art 16, Art. 25(2)	Art. 3, Art. 23, Art. 24	Arts. 3, Art. 10, Art. 12(2) (a)	All		All

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.



**Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Life	Art. 4	Art. 2		Art. I	Art. 4
Torture or Cruel, Inhuman or Degrading Treatment	Art. 5	Art. 3			Art. 5(2)
Arbitrary Arrest and Detention	Art. 6	Art. 5		Art. XXV	Art. 7(3)
Fair Trial	Art. 7	Art. 6		Art. XVIII	Art. 8
Privacy		Art. 8		Art. V	Art. 11
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Assembly and Association	Art. 10, Art. 11	Art. 11		Art. XXI, Art. XXII	Art 15, Art. 16
Bodily Integrity					
Non-discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Women and Children	Art. 18(3)		Art. 7, Art. 8, Art. 17	Art. VII	Art. 17, Art. 19

**Table I: Harm Reduction and the right to life**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A government authorizes, or fails to investigate, the murder of suspected drug traffickers as part of a crackdown on drugs.</li> <li>• An ambulance refuses to respond to a drug overdose because the underlying activity is “illegal.”</li> <li>• A government imposes the death penalty for drug-related offenses.</li> <li>• Drug users die in locked rehabilitation clinics or hospital wards, such as fire incidents in Peru in 2012 and in Moscow in 2006.</li> <li>• The government arbitrarily closes down a health service provided to drug users.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 6(1)</b> Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.</p> <p><b>ICCPR 6(2)</b> In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgment rendered by a competent court.</p>	<p><b>HRC:</b> Expressing concern to <b>Thailand</b> over the extrajudicial killing of people who use drugs. Also stating definitively that capital punishment for drug offences is in violation of the ICCPR. CCPR/CO/84/THA (2005).</p> <p><b>HRC:</b> Stating to <b>Kuwait</b> that the “committee notes the implementation of the de facto moratorium on executions in the state party since 2007. However, it is concerned about: ... (b) the large number of offences for which the death penalty can be imposed, including vague offences relating to internal and external security and drug-related crimes. CCPR/C/KWT/CO/2 (2011).</p>
<p><b>CRC 6(1).</b> States Parties recognize that every child has the inherent right to life.</p> <p><b>CRC 6(2).</b> States Parties shall ensure to the maximum extent possible the survival and development of the child.</p>	<p><b>CRC:</b> Recommending <b>Ukraine</b> “ensure that criminal laws do not impede access to such services, including by amending laws that criminalize children for possession or use of drugs.” CRC/C/UKR/CO/3-4 (CRC, 2011).</p> <p><b>CRC:</b> Recommending <b>Denmark</b> “ensure that children who use drugs and abuse alcohol are treated as victims and not as criminals.” CRC/C/DNK/CO/3 (CRC, 2005).</p>

Human Rights Standards	Case Law
<p><b>ECHR 2(1)</b> Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.</p>	<p><b>ECtHR:</b> Holding that a violation of the right to life occurs “where it is shown that the authorities . . . put an individual’s life at risk through the denial of health care which they have undertaken to make available to the population generally.” <i>Cyprus v. Turkey</i>, 25781/94, para. 721 (May 10, 2001).</p>

**Other Interpretations**

**SR Torture:** “In the Special Rapporteur on torture’s view, drug offences do not meet the threshold of most serious crimes. Therefore, the imposition of the death penalty on drug offenders amounts to a violation of the right to life, discriminatory treatment and possibly, as stated above, also their right to human dignity.” Report of the Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment for the 10th session of the Human Rights Council (2009), <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf>.

**SR Torture:** “Many states, commendably, will not extradite those who may face the death penalty. This is of particular relevance to drug policy due to the number of death sentences handed down and executions carried out for drug offences each year. While capital punishment is not prohibited entirely under international law, the weight of opinion indicates clearly that drug offences do not meet the threshold of “most serious crimes” to which the death penalty might lawfully be applied. In addition, States that have abolished the death penalty are prohibited to extradite any person to another country where he or she might face capital punishment.” Letter to CND Chairperson Ms. Selma Ashipala-Musavyi from Manfred Nowak, Special Rapporteur on the question of torture, and Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, December 10, 2008.

**The Death Penalty for Drug Offenses:** A Violation of Human Rights Law by the International Harm Reduction Association, available at: [www.ihra.net/files/2010/07/01/DeathPenaltyReport2007.pdf](http://www.ihra.net/files/2010/07/01/DeathPenaltyReport2007.pdf).

**India:** Overturns mandatory death sentence for convictions for drug trafficking in July 2011, declaring Section 31A of the Narcotic Drugs and Psychotropic Substances Act, 1985 (NDPS Act) unconstitutional.

**Table 2: Harm reduction and freedom from torture and cruel, inhuman, and degrading treatment, including in prisons**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Police or security officers beat and injure people suspected of using drugs.</li> <li>• Investigators force drug suspects into withdrawal from heroin in order to extract confessions.</li> <li>• A government imposes lengthy mandatory prison sentences for minor drug-related offenses.</li> <li>• Persons convicted of drug offenses are detained and committed to treatment in overcrowded and unsanitary facilities, without access to medical services.</li> <li>• Interruption of medical treatment in pretrial detention—e.g., opioid substitution treatment.</li> <li>• Drug users are denied mental health treatment while in prison, jail, or drug treatment.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 7:</b> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.</p>	<p><b>HRC:</b> Expressing concern about high rates of HIV and TB in <b>Ukraine</b>, and recommended that Ukraine provide hygienic facilities, assure access to health care and adequate food, and reduce the prison population, including by using alternative sanctions. CCPR/C/UKR/CO (2006).</p>

**Table 2(cont.)**

Human Rights Standards	Case Law
<b>ECHR 3:</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.	<p><b>ECtHR:</b> Holding that refusal of medical treatment to an HIV-positive detainee held on drug charges violated Article 3. <i>Khudobin v. Russia</i>, 59696/00 (Oct. 26, 2007).</p> <p><b>ECtHR:</b> Holding that forcing a drug suspect to regurgitate to retrieve a balloon of heroin violated Article 3. <i>Jalloh v. Germany</i>, 54810/00 (July 11, 2006).</p> <p><b>ECtHR:</b> Holding that the UK government breached Article 3 by failing to provide necessary medical care to a heroin dependent woman who died in a UK prison while serving a four-month sentence for theft. <i>McGlinchey and others v. UK</i>, 50390/99 (Apr. 29, 2003).</p>

**Other Interpretations**

**SR Torture:** “From a human rights perspective, drug dependence should be treated like any other health-care condition. ... denial of medical treatment and/or absence of access to medical care in custodial situations may constitute cruel, inhuman or degrading treatment or punishment and is therefore prohibited under international human rights law. ... Given that lack of access to pain treatment and opioid analgesics for patients in need might amount to cruel, inhuman and degrading treatment, all measures should be taken to ensure full access and to overcome current regulatory, educational and attitudinal obstacles to ensure full access to palliative care.” Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment for the 10<sup>th</sup> session of the Human Rights Council (2009).

**SR Torture:** Recommending that **Kazakhstan** “initiate harm-reduction programmes for drug users deprived of their liberty, including by providing substitution medication to persons and allowing needle exchange programmes in detention.” A/HRC/13/39/Add.3 (SR Torture, 2009)

**SR Torture:** Noting of **Indonesia** that in police stations, “in particular in urban areas, torture and ill-treatment is used routinely to extract confessions or in the context of drug charges to reveal dealers/suppliers.” A/HRC/7/3/Add.7 (SR Torture, 2008)

**Declaration on the Protection of All Persons from Being Subjected to Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment**, Art. 5: “The training of law enforcement personnel and of other public officials who may be responsible for persons deprived of their liberty shall ensure that full account is taken of the prohibition against torture and other cruel, inhuman or degrading treatment or punishment.”

**Standard Minimum Rules for Non-custodial Measures** (1990) (“Tokyo Rules”), Art. 1.1: “provide a set of basic principles to promote the use of non-custodial measures, as well as minimum safeguards for persons subject to alternatives to imprisonment.”

**ECOSOC**, United Nations Rules for the Treatment of Women Prisoners and Non-Custodial Measures for Women Offenders (“Bangkok Rules”). [www.un.org/en/ecosoc/docs/2010/res%202010-16.pdf](http://www.un.org/en/ecosoc/docs/2010/res%202010-16.pdf).

**Code of Conduct for Law Enforcement Officials**, Art. 2: “In the performance of their duty, law enforcement officials shall respect and protect human dignity and maintain and uphold the human rights of all persons.”

**Body of Principles for the Protection of All Persons Under Any Form of Detention or Imprisonment, Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.**

**Table 3: Harm reduction and freedom from arbitrary arrest and detention**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Drug users are arrested or detained based on planted evidence or evidence obtained through an illegal search or seizure.</li> <li>• Drug users are imprisoned on criminal charges without a fair trial.</li> <li>• Drug users are committed to forced treatment or detoxification without their consent.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 9(1):</b> Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.</p>	<p><b>HRC General Comment 8 (1):</b> Has held that protections under Article 9 apply to all forms of detention, including for “drug addiction.”</p> <p><b>HRC:</b> Noting to <b>New Zealand</b> that “the finding of an infringement of the presumption of innocence in criminal legislation related to drug possession by the Supreme Court has not yet led to amendments of the relevant legislation.” CCPR/C/NZL/CO/5 (HRC, 2010)</p> <p><b>HRC:</b> Has expressed concern in <b>Mauritius</b> that bail is not allowed for persons arrested or held in custody for the sale of drugs, urging the government to “review the Dangerous Drugs Act in order to enable judges to make a case-by-case assessment on the basis of the offence committed.” CCPR/CO/83/MUS (2005).</p> <p><b>HRC:</b> Has expressed concern in <b>Ireland</b> about the 7-day period of detention without charge under the Drug Trafficking Act (2005).</p>
<p><b>CRC 37(b)</b> No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time.</p>	<p><b>CRC General Comment 10:</b> Noting that “the rights of a child deprived of his/her liberty, as recognized in CRC, apply with respect to ... children placed in institutions for the purposes of care, protection or treatment” including drug treatment.</p> <p><b>CRC:</b> Has expressed concern in <b>Vietnam</b> about the treatment of children in drug detention centers and recommended that the government “Take all necessary measures to prevent, prohibit and protect children administratively detained in connection with drug addiction problems from all forms of torture or other cruel, inhuman and degrading treatment or punishment.” CRC/C/VNM//CO/3-4 (2011).</p> <p><b>CRC:</b> Has expressed concern in <b>Brunei Darussalem</b> “that children abusing drugs may be placed in a closed institution for a period of up to three years” and recommended that the government “develop non-institutional forms of treatment of children who abuse drugs and make the placement of children in an institution a measure of last resort” (2003).</p>

Table 3(cont.)

Human Rights Standards	Case Law
<p><b>ECHR 5(1):</b> Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:</p> <p>(a) the lawful detention of a person after conviction by a competent court;</p> <p>(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants.”</p>	<p><b>ECtHR:</b> The applicant’s sentence for drug trafficking required placement in a prison or State hospital where he could receive treatment for drug addiction but the applicant was placed in an ordinary prison. While a detention must take place “in accordance with a procedure prescribed by law” and be “lawful”, he Court finds that the applicant’s “detention” was the consequence of his conviction as a drug trafficker. The Court found that only Art. 5(1)(a) applied in this case and that while the implementation of the sentence does not have any bearing on the lawfulness of a deprivation of liberty. Therefore, the Court found no violation of Art. 5(1). <i>Bizzotto v. Greece</i>, 22126/93 (November 15, 1996).</p> <p><b>ECtHR:</b> A person charged with an offence must always be released pending trial unless the State can show that there are “relevant and sufficient” reasons to justify the continued detention. In this case, the applicant was accused of absconding investigations for his charges of drug trafficking. The Court held that the “gravity of the charges cannot by itself serve to justify long periods of detention on remand.” <i>Fursenko v. Russia</i>, 26386/02 (April 24, 2008).</p>
<p><b>ACHR 7(1):</b> Every person has the right to personal liberty and security.</p> <p><b>ACHR 7(2):</b> No one shall be deprived of his physical liberty except for the reasons and under the conditions established beforehand by the constitution of the State Party concerned or by a law established pursuant thereto.</p> <p><b>ACHR 7(3):</b> No one shall be subject to arbitrary arrest or imprisonment.</p> <p><b>ACHR 7(4)-(6):</b> Relating to rights of detained persons.</p>	<p><b>IACHR:</b> Two men were held in custody for suspicion of their involvement in international drug trafficking. The men were taken into custody and were held incommunicado for five days and were not advised of their rights, not provided any reasons for custody, or taken before a judge. The men were held in custody for a year despite lack of evidence to convict them. The Court found that the State violated Art. 7(3) “owing to the lack of due justification in the adoption and maintenance of the remand in custody” [para. 119]. <i>Chaparro Álvarez and Lapo Iñiguez v. Ecuador</i> (November 21, 2007).</p>

### Other Interpretations

**WG Arbitrary Detention: Concluding to Italy** that “the system of open-ended “security measures” for persons considered “dangerous” on the basis of mental illness, drug-addiction or otherwise might not contain sufficient safeguards.” A/HRC/10/21/ADD.5 (WG Arbitrary Detention, 2009)

**WG Arbitrary Detention:** From 2003-2005, has expressed concern about arbitrary detention of “drug addicts” and “people suffering from AIDS”; recommended that persons deprived of their liberty on health grounds “have judicial means of challenging their detention”; concluded that bail conditions can be difficult to meet for people who use drugs; and recommended that states prevent over-incarceration of vulnerable groups.

**UN Standard Minimum Rules for Non-custodial Measures (Tokyo Rules)**, adopted by GA Res 45/110 (December 14, 1990), Para. 2.3: “In order to provide greater flexibility consistent with the nature and gravity of the offence, with the personality and background of the offender and with the protection of society and to avoid unnecessary use of imprisonment, the criminal justice system should provide a wide range of non-custodial measures, from pre-trial to post-sentencing dispositions. The number and types of non-custodial measures available should be determined in such a way so that consistent sentencing remains possible.”

**Code of Conduct for Law Enforcement Officials** (1979)

**Basic Principles on the Use of Force and Firearms by Law Enforcement Officials** (1990)

**Arab Charter on Human Rights: Art. 14(1).** Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest, search or detention without a legal warrant.

**Art. 14(2).** No one shall be deprived of his liberty except on such grounds and in such circumstances as are determined by law and in accordance with such procedure as is established thereby.

**Table 4: Harm reduction and the right to a fair trial**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• An individual is convicted of drug charges after an undercover police officer lures them into committing a drug offense.</li> <li>• A detainee is kept in pre-trial detention for drug charges for an unreasonable length of time.</li> <li>• An individual is convicted on a drug offense without trial.</li> <li>• An individual is convicted of a drug charge based on evidence obtained during an illegal police search of his or her home.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 14(2):</b> Everyone charged with a criminal offence shall have the right to be presumed innocent until proved guilty according to law.</p>	<p><b>HRC:</b> Noting of <b>New Zealand</b> that “the finding of an infringement of the presumption of innocence in criminal legislation related to drug possession by the supreme court has not yet led to amendments of the relevant legislation” violates Article 9 and 14 of the ICCPR. CCPR/C/NZL/CO/5 (HRC, 2010).</p>
Human Rights Standards	Case Law
<p><b>ECHR 6(1):</b> In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law. . .</p> <p><b>ECHR 6(2):</b> Everyone charged with a criminal offence shall be presumed innocent until proved guilty according to law.</p>	<p><b>ECtHR:</b> Held that where the activity of undercover agents instigates a drug offence and there is nothing to suggest the offence would have been committed without the police’s intervention, this constitutes “incitement,” and evidence obtained as a result cannot be used against a defendant. The Court examined “whether the proceedings as a whole, including the way in which the evidence was obtained, were fair “and found that “the police’s intervention and the use of the resultant evidence in the ensuing criminal proceedings against the applicant irremediably undermined the fairness of the trial.” <i>Vanyan v. Russia</i>, 53203/99 (December 15, 2005). See also, <i>Teixeira de Castro v. Portugal</i>, 25829/94 (June 9, 1998).</p> <p><b>ECtHR:</b> Applying the above cases in 2007, the Court held that a Russian trial court should have considered evidence that a defendant facing drug charges had been entrapped by the police, especially considering that he did not have a criminal record and the only allegations of his involvement in drug dealing came from a police informant. <i>Khudobin v. Russia</i>, 59696/00 (October 26, 2007).</p> <p><b>ECtHR:</b> The Court lists criteria defining what constitutes police entrapment, but does not find a violation of Art. 6 in this case. <i>Bannikova v. Russia</i>, 18757/06 (November 4, 2010).</p>

**Other Interpretations**

**Charter of Fundamental Rights of the European Union**, Arts. 47-50: “right to an effective remedy and to a fair trial,” “presumption of innocence and right of defence,” “principles of legality and proportionality of criminal offenses and penalties,” and “right not to be tried or punished twice in criminal proceedings for the same criminal offense.”



**Table 5: Harm reduction and the right to privacy**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Police are authorized to arrest or detain people based on suspected drug use, without having to prove possession or trafficking of drugs.</li> <li>• Police are authorized to test the urine of anyone suspected of using drugs.</li> <li>• School officials are authorized to conduct invasive searches of children and random drug testing.</li> <li>• Government maintains registries of suspected drug users.</li> <li>• Doctor discloses a patient’s history of drug use or addiction without consent.</li> <li>• Clinic shares lists of registered drug users with law enforcement.</li> <li>• Police raid the home of a suspected drug user without evidence or judicial authorization.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 16(1):</b> No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence, nor to unlawful attacks on his or her honour and reputation.</p> <p><b>CRC 16 (2)</b> The child has the right to the protection of the law against such interference or attacks.</p>	<p><b>CRC General Comment No. 4 (11):</b> “Health-care providers have an obligation to keep confidential medical information concerning adolescents, bearing in mind the basic principles of the Convention. Such information may only be disclosed with the consent of the adolescent, or in the same situations applying to the violation of an adult’s confidentiality. Adolescents deemed mature enough to receive counselling without the presence of a parent or other person are entitled to privacy and may request confidential services, including treatment.” CRC/GC/2003/4 (2003).</p>

Human Rights Standards	Case Law
<p><b>ECHR 8(1):</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><b>ECHR 8(2):</b> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p><b>ECtHR:</b> The Court found that there was no compelling reason for monitoring letter correspondence to a prisoner facing drug charges and who was suspected as an illicit drug user. Although the law requires that letters addressed to prisoners are always opened in front of them, the Court found that the State must respect the confidentiality of letters from official authorities, in this case the Commission’s Secretariat. <i>Peers v. Greece</i>, 28524/95 (April 19, 2001)</p>

**Other Interpretations**

**Declaration on the Promotion of Patients’ Rights in Europe**

Art. 4.1: All information about a patient’s health status . . . must be kept confidential, even after death.  
 Art. 4.8: Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy . . . .”

**European Convention on Human Rights and Biomedicine**, Art 10(1): “Everyone has the right to respect for private life in relation to information about his or her health.”

**US Supreme Court:** ruling that Arizona school officials’ strip search of a 13-year-old girl suspected of possessing painkillers violated the Fourth Amendment, despite the school’s zero-tolerance drug policy. *Safford Unified Sch. Dist. #1 v. Redding*, No. 08–479, 129 S. Ct. \_\_\_ (2009).

## Table 6: Harm Reduction and freedom of expression and information

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Drug users are denied information about HIV prevention, harm reduction, and safer drug use.</li> <li>• Government bans publications about drug use or harm reduction, claiming they represent propaganda for illegal activity.</li> <li>• The government shuts down websites providing information about harm reduction. See, <a href="http://www.hrw.org/news/2012/02/08/russia-government-shuts-hiv-prevention-group-s-website">www.hrw.org/news/2012/02/08/russia-government-shuts-hiv-prevention-group-s-website</a>.</li> <li>• Government officials harass or detain individuals who speak publicly in favor of needle exchange, methadone, or other harm reduction measures.</li> <li>• NGOs are compelled to oppose harm reduction as a condition of government funding for work on HIV prevention.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR General Comment 14:</b> Noting that states have a responsibility, inter alia, to refrain from “applying coercive medical treatments, unless on an exceptional basis for the treatment of mental illness or the prevention and control of communicable diseases,” and to refrain from “censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information, as well as from preventing people’s participation in health-related matters.”</p> <p><b>CESRC:</b> Recommending that <b>Estonia</b> “intensify its efforts with regard to preventing drug use, including through education and awareness-raising programmes, and expansion of the provision of drug substitution therapy.” E/C.12/EST/CO/2 (CESCR, 2011).</p>

Human Rights Standards	Treaty Body Interpretation
<p><b>ECHR 10(1):</b> Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This Article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.</p> <p><b>ECHR 10(2):</b> The exercise of these freedoms, since it carries with it duties and responsibilities, may be subject to such formalities, conditions, restrictions or penalties as are prescribed by law and are necessary in a democratic society.</p>	<p><b>ECtHR:</b> This case arises from <i>Campbell v. MGN</i>, in which the supermodel Naomi Campbell was awarded damages for breach of confidence (privacy) for the publication of her drug addiction and treatment. The ECtHR held that the finding in the original case that the publication was in breach of confidence did not violate the publisher’s right to freedom of expression. <i>MGN Limited v. The United Kingdom</i>, 39401/04 (January 18, 2011).</p> <p><b>ECtHR:</b> The applicant company complained about the injunction imposed on it against reporting on the arrest and conviction of a celebrity for drug use. The Court found that the injunction violated Art. 10. <i>Axel Springer AG v. Germany</i>, no. 39954/08 (February 7, 2012).</p>

## Table 7: Harm reduction and freedom of assembly and association

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Public authorities refuse to register a drug user association.</li> <li>Police break up a peaceful demonstration against drug laws.</li> <li>Police threaten a group of people at a community meeting providing information or support. See en.rylkov-fond.org.</li> <li>People who use or possess drugs are subject to arrest, imprisonment, and fines, such as the case of Cambodia's 2011 Law on Drug Control (Royal Kram, NS/RKM/0112/001).</li> <li>A small group of people using drugs together can be charged with 'criminal conspiracy' under the law.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 21:</b> The right of peaceful assembly shall be recognized. No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.</p> <p><b>ICCPR 22 (1):</b> Everyone shall have the right to freedom of association with others ... (2) No restrictions may be placed on the exercise of this right other than those which are prescribed by law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.</p>	None

### Other Interpretations

**Charter of Fundamental Rights of the European Union, Art. 12(1):** Everyone has the right to freedom of peaceful assembly and to freedom of association at all levels, in particular in political, trade union and civic matters, which implies the right of everyone to form and to join trade unions for the protection of his or her interests.

## Table 8: Harm reduction and right to bodily integrity

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>A suspected drug user is abused by police.</li> <li>Police fail to investigate a case of domestic violence against a drug-using woman.</li> <li>Doctors compel a drug-using pregnant woman to undergo an abortion.</li> <li>Police fail to investigate the assault or murder of a person suspected of using drugs, blaming it on "gang violence."</li> </ul>
<p><b>Note:</b> The right to bodily integrity is not specifically recognized under the <b>ICCPR</b> or <b>ICESCR</b>, but has been interpreted to be part of the right to security of the person, to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health.</p> <p>Similarly, the right to bodily integrity is not specifically recognized in <b>CEDAW</b>, although CEDAW has been widely interpreted to include the right to protection from violence against women.</p>

**Table 8(cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 2</b> States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women.</p> <p><b>CEDAW 3</b> States Parties shall take ... all appropriate measures, including legislation, to ensure the full development and advancement of women, for the purpose of guaranteeing them the exercise and enjoyment of human rights and fundamental freedoms on a basis of equality with men.</p>	<p><b>CEDAW:</b> explaining to <b>Thailand</b> that “sexual harassment, rape, domestic violence and marital rape, whether in the family, the community or the workplace, constitute violations of women’s right to personal security and bodily integrity.” CEDAW/C/1999/1/L.1/Add.6 (1999).</p>

**Other Interpretations**

**Working Group on Enforced or Involuntary Disappearances:** Has noted, “An aspect of disappearances that has been underreported in the past and continues at the present time relates to the way in which acts of disappearance are perpetrated in conjunction with other gross violations, with targets drawn from among the most vulnerable groups in society. . . . Common examples brought to our notice were: disappearances, combined with “social cleansing,” the urban poor, the unemployed, and the so-called “undesirables,” including prostitutes, petty thieves, vagabonds, gamblers and homosexuals as the victims.”

**SR Violence Against Women:** Recommending to **Mexico** to “investigate with due diligence all instances of alleged violence against women whether it occurs in home, in community, or workplace with particular emphasis on connections between violence against women and drug and human trafficking; prosecute perpetrators; grant prompt and adequate compensation and support to survivors.” E/CN.4/2006/61/Add.4 (2006)

**SR Violence Against Women:** Noting of **Sweden** that while in “recent years, the shelter movement has created specialized institutions for young women and teenage girls exposed to violence. Other groups with special needs are still underserved. For example, women with severe alcohol or drug problems are usually not given access to existing shelters if they face violence. Unless they agree to enter an addiction rehabilitation programme (and actually find a place), they face a protection gap.” A/HRC/4/34/Add.3 (2006).

**The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment** (2001) stated that “every competent patient...should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances.

**The European Charter of Patients’ Rights** sets out the right to informed consent. “A patient has the right to refuse a treatment or a medical intervention and to change his or her mind during the treatment, refusing its continuation.” [Art. 4]. Moreover, a patient has “the right to freely choose from different treatment procedures and providers on the basis of adequate information.” [Art. 5].

**The Declaration on the Promotion of Patients’ Rights in Europe**, Art. 3.1, 3.2: “The informed consent of the patient is a prerequisite for any medical intervention,” and “[a] patient has the right to refuse or halt a medical intervention.”

**European Convention on Human Rights and Biomedicine**, Art 5: An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

**Table 9: Harm reduction and the right to non-discrimination**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A person is denied work, housing, health care, education, or access to goods and services due to actual or suspected drug use.</li> <li>• Police disproportionately arrest migrants and racial minorities for drug offenses, such as in the United States. See Bryan Stevenson, “Testimony on Criminal Justice for the UN Special Rapporteur on Racism” (2008), <a href="http://www.eji.org/files/05.28.08%20UNtestimonyonRace.pdf">www.eji.org/files/05.28.08%20UNtestimonyonRace.pdf</a>.</li> <li>• People who use drugs are underrepresented in HIV treatment programs despite constituting a majority of people living with HIV, especially women.</li> </ul>

**Table 9(cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICERD 2(1):</b> States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races.</p> <p><b>ICERD 2(2):</b> States Parties shall, when the circumstances so warrant, take, in the social, economic, cultural and other fields, special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms.</p>	<p><b>CERD:</b> has recommended that governments “should pay the greatest attention to the following possible indicators of racial discrimination: . . . The proportionately higher crime rates attributed to persons belonging to those groups, particularly as regards petty street crime and offences related to drugs and prostitution, as indicators of the exclusion or the non-integration of such persons into society” (2005).</p>

**Other Interpretations**

- SR Health:** Expressed concern that in **Romania** “the stigma associated with commercial sex work and injecting drug use, for example, affects how people engaged in these activities are often treated by health-care workers, especially when requesting services such as tests for sexually transmitted infections” and encouraged the government to combat discrimination that creates barrier to services (2005).
- SR Adequate Housing:** Recommended that the **United States** “federally prohibit the use of criteria such as drug tests and criminal records, for gaining access to subsidized housing.” A/HRC/13/20/Add.4 (2010).
- SR Violence Against Women:** Expressing concern that in the **United States**, “[r]acial profiling by law enforcement in the ‘war on drugs’ is a prominent issue for African-American women” and recommending that the government “[e]xplore and address the root causes, including the multiple and intersectional challenges, which lead to the increasing number of immigrant and African-American women in prisons and detention facilities.” A/HRC/17/26/Add.5 (2011).
- UN Secretary-General Ban Ki-moon’s** message for the International Day against Drug Abuse and Illicit Trafficking (June 23, 2008): “No one should be stigmatized or discriminated against because of their dependence on drugs.” [www.un.org/News/Press/docs/2008/sgsm11652.doc.htm](http://www.un.org/News/Press/docs/2008/sgsm11652.doc.htm)
- European Convention on Human Rights and Biomedicine 3:** Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.
- Covenant on the Rights of the Child in Islam, as adopted by the Organization of the Islamic Conference (OIC) 15:** The child is entitled to physical and psychological care and lists a number of concrete features of this entitlement, including: the right to necessary measures to reduce infant and child mortality rates; to preventive medical care; to the control of disease and malnutrition; and to protection from narcotics, intoxicants and other harmful substances.
- Report of the Working Group of experts on people of African descent:** noting that in the United States, “Whereas the available evidence shows that people of African descent use illegal drugs at approximately the same rate as white people, they are 10 times more likely, on a per capita basis, to go to prison for drug-related offences.” A/HRC/15/18 (2010).

**Table 10: Harm reduction and the right to the highest attainable standard of health**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Drug users or suspected drug users are turned away from hospitals or treated with stigma and judgmental attitudes in the health care system.</li> <li>• Government officials ban needle exchange programs or confiscate syringes from drug users, claiming they promote illegal activity.</li> <li>• Government bans substitution therapy with methadone.</li> </ul>

Table 10 (cont.)

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p> <p><b>ICESCR 12(2):</b> The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases.</p>	<p><b>CRC General Comment No. 3:</b> Has commented that governments “are obligated to ensure the implementation of programs which aim to reduce the factors that expose children to the use of substances, as well as those that provide treatment and support to children who are abusing substances.”</p> <p><b>CESRC:</b> Recommending that <b>Estonia</b> “intensify its efforts with regard to preventing drug use, including through education and awareness-raising programmes, and expansion of the provision of drug substitution therapy. Furthermore, the committee encourages the state party to continue expanding the needle exchange programme.” E/C.12/EST/CO/2 (CESCR, 2011).</p> <p><b>CESCR:</b> After expressing concern about the spread of drug addiction and the ban on certain medical treatments for drug dependence, recommended that <b>Russia</b> “apply a human rights-based approach to drug users so that they do not forfeit their basic right to health.” They also recommended that Russia “provide clear legal grounds and other support for the internationally recognized measures for HIV prevention among injecting drug users, in particular the opioid substitution therapy with use of methadone and buprenorphine, as well as needle and syringe, and overdose prevention programmes.” E/C.12/RUS/CO/5 (CESCR, 2011).</p> <p><b>CESRC:</b> Recommending that <b>Kazakhstan</b> “ensure that methadone as substitute drug dependence therapy is made accessible to all drug dependents.” E/C.12/KAZ/CO/1 (2010).</p> <p><b>CESRC:</b> Recommending to <b>Mauritius</b> to “undertake a comprehensive approach to combat its serious drug problem. In order to achieve the progressive realization of the right to the highest attainable standard of physical and mental health for people who inject drugs and to ensure that this group may benefit from scientific progress and its applications (art. 15, para. 1(b)), the State party should implement in full the recommendations made by the World Health Organization in 2009 designed to improve the availability, accessibility and quality of harm reduction services, in particular needle and syringe exchange and opioid substitution therapy with methadone. People who use drugs should be a key partner in this initiative. As a matter of urgency, the State party should:</p> <ul style="list-style-type: none"> <li>(a) Scale up needle and syringe programmes to all geographical areas. The Government should amend the Dangerous Drugs Act of 2000 to remove prohibitions on distributing or carrying drug paraphernalia as these impede HIV prevention services; (b) Implement pilot prison needle and syringe exchanges and opioid substitution therapy programmes based on international best practice standards; (c) Remove age barriers to accessing opioid substitution therapy and develop youth-friendly harm reduction services tailored to the specific needs of young people who use drugs;</li> <li>(d) Remove restrictions on access to residential shelters for women who use drugs; (e) Make hepatitis C treatment freely available to all injecting drug users; (f) With regard to addicted persons, consider decriminalization and public health-based measures such as prescription of buprenorphine. E/C.12/MUS/CO/4 (2010).</li> </ul> <p><b>CESRC:</b> Recommending that <b>Poland</b> “take measures to ensure that effective treatment of drug dependence is made accessible to all, including to those in detention.” E/C.12/POL/CO/5 (2009).</p> <p><b>CESRC:</b> Recommending that <b>Ukraine</b> “make drug substitution therapy and other HIV prevention services more accessible for drug users.” E/C.12/UKR/CO/5 (CESCR, 2008).</p> <p><b>CESCR:</b> Expressed concern in <b>Tajikistan</b> with “the rapid spread of HIV...in particular among drug users, prisoners, sex workers,” and recommended that the government “establish time-bound targets for extending the provision of free testing services, free treatment for HIV and harm reduction services to all parts of the country” (2006).</p>



## Table 10 (cont.)

### Other Interpretations

**SR Health:** Chapters of this report include the impact of drug control on the right to health including deterrence from accessing services and discrimination; and a human rights-based approach to drug control, including harm reduction and decriminalization. A/65/255 (2010).

**SR Health:** After an in-depth review of harm reduction in **Poland**, recommends that Poland:

(a) Ensure that needle and syringe programmes, opioid substitution therapy and other harm reduction strategies become widely available throughout the country; (b) To establish, without further delay, an opioid substitution programme in the Tri-City region of Gdansk, Sopot and Gdynia; (c) Amend the National Law on Counteracting Drug Addiction to avoid penalization of the possession of minute quantities of drugs, in order to foster access to substitution therapy for people using drugs; (d) Ensure the informed and active participation of people using drugs and other marginalized groups at the national, regional, and local level in the establishment of policies and programmes; (e) Include the participation of people living with HIV and those groups most at risk of HIV in HIV/AIDS-related educational projects and campaigns; (f) Ensure the enactment and implementation of a comprehensive antidiscrimination and equality law to help ensure the full enjoyment of the right to health, based on equality and non-discrimination within the State. A/HRC/14/20/Add.3 (2010).

**SR Health:** Recommending to **Sweden** that “the Government has a responsibility to ensure the implementation, throughout Sweden and as a matter of priority, of a comprehensive harm-reduction policy, including counselling, advice on sexual and reproductive health, and clean needles and syringes. A/HRC/4/28/Add.2 (2007).

**SR Health:** Expressed concern that the Anti-Narcotics Campaign in **Thailand**, coupled with limited access to harm reduction services, had inadvertently created the conditions for a more extensive spread of HIV in Thailand. (2005).

**SR Health:** Expressed concern in Romania that “the stigma associated with commercial sex work and injecting drug use, for example, affects how people engaged in these activities are often treated by health-care workers, especially when requesting services such as tests for sexually transmitted infections” and encouraged the government to combat discrimination that creates barriers to services (2005).

Decision 74/10, **Flexibility of Treaty Provisions as Regards Harm Reduction Approaches**, prepared by UNDCP’s Legal Affairs Section, E/INCB/2002/W.13/SS.5, September 30, 2002, [www.tni.org/drugsreformdocs/un300902.pdf](http://www.tni.org/drugsreformdocs/un300902.pdf).

**Declaration on the Elimination of Violence Against Women**, G.A. Res. 48/104, UN Doc. A/RES/48/104 (December 20, 1993): Women are entitled to the equal enjoyment and protection of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. These rights include, *inter alia*: . . . (f) the right to the highest standard attainable of physical and mental health.

**WHO 1978 Declaration of Alma-Ata:** The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

**World Health Organization Constitution, preamble:** The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

**Protocol San Salvador 10(2):** In order to ensure the exercise of the right to health, the States Parties agree to recognize health as a public good, and particularly, to adopt the following measures to ensure that right: (a) Primary health care, that is, essential health care made available to all individuals and families in the community (b) Extension of the benefits of health services to all individuals subject to the State’s jurisdiction; (c) Universal immunization against the principal infectious diseases; (d) Prevention and treatment of endemic, occupational and other diseases; (e) Education of the population on the prevention and treatment of health problems, and (f) Satisfaction of the needs of the highest risk groups and of those whose poverty makes them the most vulnerable.

**The Declaration on the Promotion of Patients’ Rights in Europe**, Art. 5.3: “Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider.”

**Charter of Fundamental Rights of the European Union 35:** Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.



**Table II: Harm reduction and the rights of women and children**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Women are denied access to harm reduction services on an equal basis with men.</li> <li>• Pregnant women who use drugs are forced to undergo abortions or sterilization, or are penalized for attempting to injure their child.</li> <li>• Children and young people are denied access to objective and accurate information about drugs and are barred from existing treatment and harm reduction services through age restrictions.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(1):</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p> <p><b>CRC 33:</b> States Parties shall take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances.</p>	<p><b>CRC General Comment 3 (39):</b> Has identified that “[c]hildren who use drugs are at high risk [of HIV]” and that “injecting practices using unsterilized instruments further increase the risk of HIV transmission;” has also stated that governments “are obligated to ensure the implementation of programmes which aim to reduce the factors that expose children to the use of substances, as well as those that provide treatment and support to children who are abusing substances.”</p> <p><b>CRC:</b> Recommending to <b>Ukraine</b> to, “in partnership with non-governmental organizations, develop a comprehensive strategy for addressing the alarming situation of drug abuse among children and youth and undertake a broad range of evidence-based measures in line with the convention, and that it:</p> <p>(a) develop specialized and youth-friendly drug-dependence treatment and harm-reduction services for children and young people, building on recent legislative progress on HIV/AIDS and the successful pilot programmes for most-at-risk adolescents initiated by UNICEF; (b) ensure that criminal laws do not impede access to such services, including by amending laws that criminalize children for possession or use of drugs; (c) ensure that health and law enforcement personnel working with at-risk children are appropriately trained in HIV prevention and that abuses by law enforcement against at-risk children are investigated and punished; (d) intensify the enforcement of the prohibition of the sale of alcohol and tobacco to children and address root causes of substance use and abuse among children and youth.” CRC/C/UKR/CO/3-4 (CRC, 2011)</p> <p><b>CRC:</b> Expressed concern in <b>Armenia</b> at the criminalization of young drug users, and urged the government “to ensure that child drug abusers are not criminalized, but treated as victims in need of assistance towards recovery and reintegration.” (2004).</p> <p><b>CRC:</b> Has made country-specific recommendations on children who use drugs to <b>Iceland</b> (2012), <b>Seychelles</b> (2012), <b>Costa Rica</b> (2011), <b>Bangladesh</b> (2009), <b>Sweden</b> (2009), <b>Bulgaria</b> (2008), <b>Colombia</b> (2007), <b>Honduras</b> (2007), <b>Malaysia</b> (2007), <b>Uruguay</b> (2007), <b>Liechtenstein</b> (2006), <b>Peru</b> (2006), <b>Senegal</b> (2006), <b>Tanzania</b> (2006), <b>Albania</b> (2005), <b>Bahamas</b> (2005), <b>Denmark</b> (2005), <b>Nigeria</b> (2005), <b>Mongolia</b> (2005), <b>Armenia</b> (2004), <b>El Salvador</b> (2004), <b>Netherlands</b> (2004), <b>Sao Tome and Principe</b> (2004), <b>Indonesia</b> (2004), <b>Brunei Darussalem</b> (2003), <b>Pakistan</b> (2003), <b>Panama</b> (2003), <b>Estonia</b> (2003), <b>Ukraine</b> (2002), <b>St. Vincent and the Grenadines</b> (2002), <b>Cote D’Ivoire</b> (2001), <b>Monaco</b> (2001), <b>India</b> (2000), <b>UK</b> (2000), etc.</p>

### Other Interpretations

**SR Violence Against Women:** Recommending that the **United States** “Ensure that sentencing policies reflect an understanding of women’s levels of culpability and control with drug offenses” and “[r]eview laws that hold women responsible for their association with people involved in drug activities, and which punish them for activities of drug operations they may have little or no knowledge.” A/HRC/17/26/Add.5 (2011).

**SR Violence Against Women:** Expressed concern that the **United States** was “criminalizing a large segment of its population” through drug charges, increasingly women, and that many of these offenses “may be more appropriately handled by a community-based system of welfare and social support, as is presently the case in certain European countries” (1999).

### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>88</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>89</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>90</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>91</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>88</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>89</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>90</sup> Ibid.

<sup>91</sup> Ibid.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>92</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>92</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

## 4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF HARM REDUCTION?

This section contains nine examples of effective human rights-based work in the area of harm reduction and human rights. These are:

1. Documenting police misconduct through affidavits of drug users.
2. Thai Drug Users Network raising awareness of health and human rights issues.
3. Challenging police raids and criminalization of drug use in Hungary.
4. Harm Reduction International's engagement with human rights mechanisms.
5. Litigating the privacy of drug users versus freedom of information held by the press in the European Court of Human Rights.
6. Challenging hate speech against drug users in the press in Ireland.
7. Challenging the mandatory death penalty for drugs in India.
8. Advocating for opioid substitution treatment in Russia.
9. Litigating and advocating for methadone maintenance programs in Canadian prisons.

## Example I: Collecting affidavits to document illegal policing actions

### Project Type

Advocacy

### The Organization

Pivot Legal Society focuses its work on marginalized populations that live in Vancouver's Downtown Eastside (DTES). Believing that equality lifts everyone, Pivot employs legal, political and community outreach techniques to promote health and drug policy, protect sex workers' rights, advance accountable policing, reverse homelessness and create meaningful employment opportunities. In their own words, they are "building a movement for a just society, where dignity, fairness and compassion are firmly rooted in the law."

### The Problem

Vancouver's DTES faces a public health emergency. Residents in DTES face high rates of injection drug use and poverty, a growing sex trade, higher morbidity rates for HIV/AIDS, and skyrocketing violence. In 2002, while Vancouver did recognize the public health emergency in DTES, it combated the homelessness, drug use and sex trade with increased policing efforts. The increased policing resulted in poorer public health outcomes, higher numbers of civil liberty offenses, and a rising frequency of illegal policing actions. In this climate, Pivot calls for improved monitoring and enforcement of police actions, increased access to the complaint system, a public inquiry and a general end to the selection of those who live on society's margins in Vancouver's DTES for the infliction of special punishment.

### Actions Taken

John Richardson, lawyer, founder and, at that time, executive director of Pivot, began to collect affidavits from residents of the DTES. The goal was to document police misconduct against people who use drugs in the DTES. Over a period of nine months, Mr. Richardson worked with volunteer lawyers and law students from the University of British Columbia collecting affidavits from residents who responded to requests for affidavits made by announcements at public events, through distributed pamphlets and by a word of mouth campaign. The participants did not receive any compensation or any promise of future aid. Although designed by Mr. Richardson, the program was inspired by Mahatma Gandhi's work in 1917 with peasant farmers in Bihar, India.

The affidavits revealed impressive but quite regrettable statistics. Twenty-two witness statements and 39 victim statements reported 50 incidences of police misconduct in the DTES. Of the 39 victim statements, 26 victims reported whether they used drugs. Twenty-one of those 26 reported that they used drugs. Therefore, the affidavits revealed an apparent and particularly troubling tendency of the police to inflict punishment on drug users in Vancouver's DTES.

### Results and Lessons Learned

The affidavits were a success. They drew the public's attention to the problem of police misconduct in the DTES and catalyzed a change in policing policy in the DTES. Some of the tangible results were:

*In response to the published affidavits, retired BC Judge Josiah Wood audited Vancouver's Police Department and made recommendations similar to Pivot's. The Police Department implemented some reforms including an improved seized property handling policy and more stringent note-taking procedures for police officers.*

## Examples of Documented Violations of International Obligations

- **Torture.** Police beat those they suspected of using drugs. 12 affidavits report incidents meeting the legal definition of torture, including broken bones or teeth, head and brain injuries, flesh wounds and dog bites.
- **Discrimination.** Arrests and detentions based on ethnicity. Police refuse to aid suspected drug addicts.
- **Freedom of Movement.** Police order DTES residents out of a neighborhood. “They searched through all my stuff. When they saw that I didn’t have any drugs on me, they told me to ‘get out of Vancouver.’”
- **Arbitrary Arrest/Detention.** Police “jack-up” suspected drug addicts (arbitrary detention without arrest).
- **Bodily Integrity.** Police removed a suspected drug dealer’s pants on the street. Strip searches conducted as a matter of policy when newly arrested individuals arrive at jail.
- **Privacy.** Police raid the home of a suspected drug user without evidence or judicial authorization. Unlawful seizure of property owned by suspected drug user/dealer
- **Lack of Medical Treatment in Jail.** People are denied access to medical treatment or their medications while in the Vancouver jail.

In 2007, five years after Pivot conducted its affidavit campaign, the new chief of the Vancouver Police Department issued a formal apology, which recounted a number of acts of police misconduct. The police department disciplined officers and made 16 major policy and procedural changes.

In 2011, the provincial government implemented an Independent Investigations Office which will receive individual complaints against police departments.

The affidavit campaign did have problems, however, particularly with regards to barriers to participant participation. Women were particularly underrepresented in the campaign because of their special vulnerability to exploitation, addiction, poverty and violence. Moreover, as noted in Pivot’s report, the general DTES population had a lower than optimal participation rate due to a participant’s lack of time; fear of retribution from police officers who may target them as a result of the affidavit; belief that time spent giving the affidavit could be better spent trying to get money to buy drugs; a preference to forget about the incident; feeling that they deserved police mistreatment as a consequence of their drug use; concern that swearing information could be used to incriminate them; a lack of faith in the legal processes combined with a disbelief that reporting misconduct would will lead to any redress; and a belief that the police will lie about the incident while the affiant will not be believed because they are a drug addict and/or have a criminal record.

### Pivot Legal Society

Vancouver, Canada

E-mail: [getinvolved@pivotlegal.org](mailto:getinvolved@pivotlegal.org)

Website: [www.pivotlegal.org](http://www.pivotlegal.org)

Report: To Serve and Protect: A Report on Policing in Vancouver’s Downtown Eastside. [http://d3n8a8pro7vhmx.cloudfront.net/pivotlegal/legacy\\_url/251/toserveandprotect.pdf?1345134576](http://d3n8a8pro7vhmx.cloudfront.net/pivotlegal/legacy_url/251/toserveandprotect.pdf?1345134576).



## Example 2: Thai drug users form a network to advocate for harm reduction and human rights

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### Project Type

Advocacy

### The Organization

The Thai Drug Users' Network (TDN) formed in Bangkok, Thailand in December 2002. The organization focuses on raising awareness of health, human rights and harm reduction principles—especially as those concepts relate to experiences of arbitrary arrest, torture, discrimination in judicial and healthcare settings, and lack of access to health care information. Former injection drug users founded TDN and the organization now includes over 100 former or current drug users.

### The Problem

Most new cases of HIV in Thailand occur as a result of injection drug use. At the time of TDN's forming, needle exchange programs were illegal, drug users encountered difficulty obtaining antiretroviral drugs, opiate substitution therapy was not readily available, and stiff criminal penalties existed for illicit drug use. In February 2003, the Thai Government initiated a campaign to make Thailand “drug free.” The campaign resulted in widespread human rights abuses against IDUs, including the extrajudicial killings of over 2,200 alleged drug dealers and the incarceration of approximately 50,000 suspected drug users.

### Actions Taken

In May 2002, Paisan Suwannawong and Karyn Kaplan conducted a study on the human rights situation of IDUs in Thailand. In December 2002, Suwannawong and Kaplan released their findings to the study participants in a meeting held in Bangkok. This prompted the study participants to form TDN.

TDN was designed to address the human rights issues raised by Suwannawong and Kaplan's report. The project benefited from technical and financial support from international organizations, but was led by the Thai IDUs who commanded knowledge of the problem, a passion to effectuate a solution, credibility of their followers and respect from activists and governments around the world.

### Results and Lessons Learned

- TDN gained a seat on Thailand's official harm reduction task force and met with members of the Ministry of Public Health and the Office of Narcotics Control
- TDN and three partners received a US \$1.3 million grant from the Global Fund to Fight AIDS, TB and Malaria (despite the lack of a Country Coordinating Mechanism) to implement peer-driven HIV prevention and harm reduction programs across Thailand.
- TDN met with members of the Ministry of Public Health and the Office of Narcotics control. In July 2004, Prime Minister Shinawatra (who previously declared Thailand's drug-free campaign) reversed course and publicly committed to the harm reduction principle, eschewing punitive measures.
- The project and Global Fund grant dramatically raised the profile of IDUs in Thailand and the region, leading to their unprecedented involvement in national and multilateral policymaking, funding, and program development.

## Example 3: Challenging police raids and criminalization of drug use in Hungary through “civil obedience”

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**Project Type**

Advocacy

**The Organization**

The Hempseed Association is a Hungarian drug reform activist group. The Hungarian Civil Liberties Union is Hungary’s leading drug policy NGO.

**The Problem:**

In Hungary, police regularly raided discos and forced young club-goers to undergo urine tests. This violated privacy rights and rules of criminal procedure, and potentially forced discos underground, making it more difficult to conduct harm reduction outreach with club-goers.

**Actions Taken:**

The Hempseed Association and the Hungarian Civil Liberties Union challenged the police practice of raiding discos and conducting forced urine tests in order to catch people using drugs. Led by the Hempseed Association and with legal advice and representation from the HCLU, individuals reported to the National Police Headquarters in Budapest in the spring of 2005 to confess their non-violent drug use. The aim of this “Civil Obedience Movement” was to challenge the practice of forced urine tests and to raise the issue of decriminalization of drug use.

Every Wednesday for five weeks, “self-reporters” including celebrities appeared at police headquarters. The HCLU provided each self-reporter with a legal manual. More than 60 people self-reported in total.

The action attracted significant media attention and dominated public debate for weeks. Activists expressed their views to the media about the illegal practice of police raids and about decriminalization. HCLU made freedom-of-information requests to the police about the cost of police raids, and used the data to show the raids were not cost-effective.

**Results and Lessons Learned:**

The action succeeded in its main goal, which was to obtain a statement from the police that urine tests could only be conducted on someone following initiation of a criminal procedure against them. This effectively made urine test raids unlawful. The number of police raids seriously decreased, with very few raids occurring in 2006.

The campaign also succeeded in making decriminalization of drug use a subject of mainstream debate. More than 70 professionals working on the drug field signed a petition supporting the aims of the campaign. Three months after the action, the first-ever draft bill on decriminalization was introduced in parliament.

The campaign showed that good stories and human faces are an important and successful way of achieving media coverage of drug policy campaigns.

**Hungarian Civil Liberties Union**

Budapest, Hungary

E-mail: [tasz@tasz.hu](mailto:tasz@tasz.hu)

Website: <http://tasz.hu/en>

Drug Policy Website: [www.drogriporter.hu](http://www.drogriporter.hu)

Drug Policy Website English: <http://drogriporter.hu/en>

**The Hempseed Association (Kendermag Egyesület)**

Website: <http://www.kendermag.hu/> (Hungarian only)

## Example 4: Harm Reduction International's engagement with human rights mechanisms

### Project Type

Advocacy

### The Organization

Harm Reduction International (HRI) advocates for the human rights of drug users and documents the harms associated with drug use.

### The Problem

The total elimination of psychoactive drug use is not a practical goal. Those who are unable or unwilling to end their use of controlled drugs, alcohol, tobacco, or pharmaceutical drugs need access to treatment to reduce harms associated with their drug use. Unfortunately, many governments do not provide the necessary harm reduction programs. A health and human rights approach is needed to leverage these governments into providing not only the necessary funding, commitment and implementation of harm reduction programs but also the appropriate legal framework in which to operate those programs.

## What are Shadow Reports?

When a country is being reviewed by a human rights committee, civil society organizations are permitted to submit a report to supplement the obligatory state report. Often, many civil society organizations collaborate together to create one comprehensive report. These shadow reports provide valuable and independent insight to the human rights committee. The reports allow the human rights committee to determine whether a given country complies with its human rights obligations vis-à-vis its actions towards drug users within its borders. Shadow reports are encouraged by the committees because it ensures that the treaty body review mechanisms are more meaningful and the committees can engage in more robust analysis.

### Actions Taken

In partnership with national and international organizations, HRI submits shadow reports on various countries to various human rights treaty bodies.

#### *Committee on Economic, Social and Cultural Rights*

**Sweden** (2007/08) with Swedish Drug Users Union. <http://www2.ohchr.org/english/bodies/cescr/docs/info-ngos/sduu-ihra.pdf>.

**Poland** (2009) with Open Society Institute Global Drug Policy Program [www.ihra.net/human-rights-treaty-body-reporting](http://www.ihra.net/human-rights-treaty-body-reporting).

**Kazakhstan** (2010) with Canadian HIV/AIDS Legal Network, The Eurasian Harm Reduction Network, Anti-AIDS (Pavlodar), Equal to Equal (Almaty) and KREDO. (In Russian). [www2.ohchr.org/english/bodies/cescr/docs/ngos/IHRA\\_Kazakhstan\\_44.pdf](http://www2.ohchr.org/english/bodies/cescr/docs/ngos/IHRA_Kazakhstan_44.pdf).

**Mauritius** (2010) with Collectif Urgence Toxida. [www2.ohchr.org/english/bodies/cescr/docs/ngos/IHRA\\_CUT\\_Mauritius44.pdf](http://www2.ohchr.org/english/bodies/cescr/docs/ngos/IHRA_CUT_Mauritius44.pdf).

**Afghanistan** (2010) with Transnational Institute

**Colombia** (2010) with Institute for Policy Studies and Witness for Peace.

**Russian Federation** (2010-ongoing) with Andrey Rylkov Foundation for Health and Social Justice. [www.ihra.net/human-rights-treaty-body-reporting](http://www.ihra.net/human-rights-treaty-body-reporting).

*Committee on the Rights of the Child*

**Ukraine** (2010) with Eurasian Harm Reduction Network. [www.ihra.net/files/2011/02/10/EHRN\\_IHRA\\_Ukraine\\_report\\_CRC.pdf](http://www.ihra.net/files/2011/02/10/EHRN_IHRA_Ukraine_report_CRC.pdf)

*Committee Against Torture*

**China** with Human Rights Watch and Asia Catalyst (2008). [http://www2.ohchr.org/english/bodies/cat/docs/ngos/HRW\\_IHRA\\_AC\\_China\\_41.pdf](http://www2.ohchr.org/english/bodies/cat/docs/ngos/HRW_IHRA_AC_China_41.pdf)

## Resources for Engagement with UN Treaty Bodies

Below we provide one general guide that includes descriptions of the treaty bodies and what they do as well as an explanation of how NGOs can engage with the treaty bodies. The second resource provides training materials for engagement with UN mechanisms specific to harm reduction.

*Simple Guide to the UN Treaty Bodies*. International Service for Human Rights, [www.ishr.ch/guides-to-the-un-system/simple-guide-to-treaty-bodies](http://www.ishr.ch/guides-to-the-un-system/simple-guide-to-treaty-bodies). Also available in French.

*The UN Human Rights System and Harm Reduction Advocacy: A training package for civil society organisations*. Harm Reduction International, [www.ihra.net/human-rights-training](http://www.ihra.net/human-rights-training)

## Results and Lessons Learned

The submission of shadow reports to various UN human rights committees has had a positive impact on the committees' ability to determine a country's compliance with a human rights treaty. Frequently, shadow reports address omissions, deficiencies or inaccuracies in official government reports. Shadow reports can also influence and shape the questions asked by the committee and consequently, their concluding observations and recommendations as well. For example, by submitting a shadow report on the status of drug users in a given country, it will bring the issue to the committee's attention and perhaps trigger the committee to pose questions to government officials on its political and financial commitment to harm reduction measures. Governments are required to answer all questions posed by the committee, and this has proven to be an effective accountability mechanism for civil society.

### Harm Reduction International

London, United Kingdom

Email: [info@ihra.net](mailto:info@ihra.net)

Website: <http://www.ihra.net/>

## Example 5: The right to privacy in the context of drug treatment

*MGN Limited v. The United Kingdom*, no. 39401/04, ECtHR (January 18, 2011). Available at <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-111412>.

### Project Type

Litigation

### Organization

This is an example of an individual person that filed a lawsuit to protect her privacy.

### The Problem

The British tabloid *The Daily Mirror* (formerly known as the *Mirror*) published several articles in 2001 showing supermodel Naomi Campbell attending Narcotics Anonymous (NA) meetings. Ms. Campbell wrote to the paper stating that the article was a breach of her privacy and asked it to publish no further articles regarding her attending NA meetings. The tabloid continued to publish articles regarding Ms. Campbell attending NA meetings and once wrote, “After years of self-publicity and illegal drug abuse, Naomi Campbell whinges about privacy.”

### Procedure

The British House of Lords found MGN Limited, publisher of the *Mirror*, guilty of the tort of failing to maintain confidence by publishing an article depicting supermodel Naomi Campbell attending a Narcotics Anonymous meeting. MGN Limited appealed to the European Court of Human Rights (“ECtHR”) on the theory that the verdict violated its article 10 rights under the European Convention of Human Rights (“ECHR”) (relating to freedom of expression).

## Rights Violated

ECHR Article 8: Everyone has the right to respect for private and family life, his home and his correspondence.

### Arguments and Holdings

#### *Freedom of Expression*

Ms. Campbell acknowledged that she could not complain about the reports that she took illegal drugs, since she had previously made public claims that she did take illegal drugs. The subject of her complaint involved those “additional” materials published by the *Mirror*—that is, the reports of her attending NA meetings. Article 10 of the European Convention on Human Rights provides: “Everyone has the right to freedom of expression” but also provides that a state party may limit freedom of expression when “prescribed by law” and when it is “necessary in a democratic society.”

Since it was not disputed that a finding of a breach of confidence against the applicant amounted to an infringement on its right to freedom of expression, the issue for the court to decide was whether the restriction was necessary in a democratic society. MGN admitted that publishing the facts of Ms. Campbell's drug use and recovery efforts were sufficient to rebut her earlier statements regarding her history of drug use. The *Mirror* did not have to publish the additional materials regarding Ms. Campbell attending NA meetings to ensure the credibility of the story regarding her prior drug use. Moreover, the reports of the additional material were harmful to Ms. Campbell's continued treatment and caused a setback in her recovery efforts. Finally, the Court noted that it needed "strong reasons," which were not present in this case, to substitute its judgment for that of a national court. Therefore, since publishing the additional material was not necessary in a democratic society and since it was proscribed by law, the Court found no violation of the newspaper's right to freedom of expression under Article 10 of the European Convention on Human Rights.

#### *Right to privacy*

In a factual similar case (*Von Hannover v. Germany*, App. No. 59320/00 [June 24, 2004]), the European Court of Human Rights found that the German Constitutional Court violated Article 8 of the European Convention on Human Rights (providing the right to respect for private and family life) by denying a public figure privacy claims against a publisher. In *MGM Limited*, the European Court of Human Rights held that the House of Lords did not violate Article 10 of the European Convention on Human Rights (providing the right to freedom of speech) when it found that the tabloid had acted in breach of confidence by publishing the articles on Ms. Campbell.

#### **Commentary and Analysis**

Articles 8 and 10 are in natural tension with each other. States parties must strike an appropriate balance between the two. In determining whether the state party has succeeded in striking the appropriate balance, a court will balance the public interest that article 10, freedom of expression, is intended to protect with the individual interest that art. 8, respect for private and family life, is intended to protect.

The case demonstrates the right of drug users to privacy rights within the context of drug treatment. Narcotics Anonymous cannot operate if members cannot maintain anonymity. This case helps establish that the right to freedom of expression must be balanced with the right for respect for private and family life. MGN Limited and other members of the press in Europe do not have an unbridled right to out an individual as a Narcotics Anonymous member.



## Example 6: Contesting hate speech against drug users

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### Project Type

Advocacy

### The Organization

Harm Reduction International (HRI), the Irish Needle Exchange Forum, and the CityWide Drugs Crisis Campaign work to provide services for drug users, their families and their communities. They also provide accurate information on drug use to policy makers and battle the stigma against drug users that exists in Ireland.

### The Problem

Ian O’Doherty wrote an article for the *Irish Independent* in which he described drug users as “vermin,” “feral worthless scumbags,” and proclaimed “if every junkie in this country were to die tomorrow [,] I would cheer.”

### Actions Taken

HRI, the Irish Needle Exchange Forum and the CityWide Drugs Crisis Campaign filed a joint complaint with the Irish Press Ombudsman against the *Irish Independent* for publishing Mr. O’Doherty’s article. The complainants argued that the article violated Principles 1.1 and 8 of the Code of Practice for Newspapers and Magazines.

### Results and Lessons Learned

#### *Hate Speech:*

The Irish Press Ombudsman found that the article “was likely to cause grave offense to or stir up hatred against individuals or groups addicted to drugs on the basis of their illness.” The Independent published hate speech, which the Ombudsman would not allow under Ireland’s Principle 8.

#### *Duty of the Press.*

The Ombudsman determined that it did not have enough information to rule on the Principle 1 claim, however was clear that journalist and the press—as having an important role in contributing ideas and discourse necessary to a functioning democracy—must report the facts accurately. This obligation extends beyond Ireland to all countries in Europe.<sup>93</sup>

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<sup>93</sup> See *Pedersen a Baadsgard v. Denmark* (ECtHR) Report 2004-XI para. 78 (“protection of the right of journalists to impart information on issues of general interest requires that they should act in good faith and on an accurate actual basis and provide ‘reliable and precise’ information in accordance with the ethics of journalism.”) (citations omitted).

## Code of Practice for Newspapers and Magazines

Principle 1.1: “In reporting news and information, newspapers shall strive at all times for truth and accuracy.  
Principle 8: “Newspapers and magazines shall not publish intended or likely to cause grave offense or stir up hatred against individual or group on the basis of their race, religion, nationality, colour, ethnic origin, membership of the travelling community, gender, sexual orientation, marital status, disability, illness or age.

### Commentary and Analysis

This case study demonstrates that public expression of stigma against drug users can be categorized as hate speech. These types of comments fuel negative and oppressive attitudes towards drug users. Fighting against this level of hate speech will help change societal attitudes and work to eliminate the stigma attached to drug users.

The International Convention on Civil and Political Rights (ICCPR) also allows for states parties to restrict expression for the purpose of prohibiting hate speech. State parties are permitted to limit hate speech “for respect of the rights or reputations of others” under ICCPR article 19(3) (a). Advocacy groups may consider utilizing the human rights committee complaint mechanism or country review process to bring attention to hate speech against drug users in an effort to affect societal attitudes.

#### **Harm Reduction International**

London, England

Email: [info@ihra.net](mailto:info@ihra.net)

Website: <http://www.ihra.net/>

#### **Irish Needle Exchange Forum**

Ireland

E-mail: [info@inef.ie](mailto:info@inef.ie)

Website: <http://inef.ie/>

#### **CityWide Drugs Crisis Campaign**

Dublin, Ireland

E-mail: [info@citywide.ie](mailto:info@citywide.ie)

Website: <http://www.citywide.ie/>

## Example 7: Challenging the mandatory death penalty for drugs in India

*Mithu v. State of Punjab*, (1983) 2 S.C.C. 277 (India).  
Available at: [www.lawyerscollective.org/files/IHRN%20judgment.pdf](http://www.lawyerscollective.org/files/IHRN%20judgment.pdf).

### Project Type

Litigation

### Organization

This is an example of an individual challenging a government policy by bringing a human rights claim.

### The Problem

An Indian man who was found guilty of a repeated offense of transporting *charas* (cannabis resin) received a mandatory death sentence under section 31-A of the Narcotic Drugs and Psychotropic Substances Act.

### Procedure

On appeal from the Special Narcotic Drugs and Psychotropic Substances (NDPS) Court in Mumbai to the High Court of Judicature at Bombay.

### Arguments and Holdings

#### *Procedural Due Process*

Although the Indian Constitution does not contain an explicit reference to “due process,” numerous decisions by Indian courts over the years recognize the right as living in article 21 of the Indian Constitution (“No person shall be deprived of his life or personal liberty except according to procedure established by law.”). Moreover, Article 6 of the International Convention on Civil and Political Rights demands that “No one shall be arbitrarily deprived of his life” and that the “sentence of death may be imposed only for the most serious crimes.” Harm Reduction International argued that the mandatory death penalty of section 31-A breaks with the principle of procedural due process which holds that judges should determine sentences based on the individual criminal offense. The High Court of Judicature at Bombay agreed, reasoning that a mandatory death penalty “fails to fulfill the cardinal procedure safeguards of legitimate exercise of judicial discretion for sentencing.”

#### *Substantive Due Process*

The petitioner argued that the mandatory death penalty was unconstitutional because it violated the defendant’s substantive due process rights. Citing article 7 of the ICCPR as interpretative support, the petitioner argued that the mandatory death penalty violated his substantive due process rights against torture. The court disagreed, arguing that (a) Indian municipal law that is in accordance with the Indian Constitution trumps the requirements of International agreements and that (b) Indian courts have consistently held that the death penalty is not cruel.

*Separation of Powers:* The petitioner argued that allowing section 31-A to stand would be to allow the legislature to circumscribe the power of Indian courts to determine penalties for offenses prescribed by section 31-A, leaving the courts with the ability to determine guilt or innocence, only. This argument clearly concerned the court, as it reasoned that section 31-A “completely takes away the judicial discretion, nay, abridges the entire procedure for administration of criminal justice of weighing the aggravating and mitigating circumstances in which the offense was committed as well as that of the offender.”

**Violations of India's Constitution**

**Article 21:** No person shall be deprived of his life or personal liberty except according to procedure established by law.

**Violations of the ICCPR**

**Article 7:** “No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.”

*Equal Protection*

The petitioner made a strong but ultimately unsuccessful equal protection attack on the NDPS. Article 14 of the Indian Constitution provides that “[t]he State shall not deny to any person equality before the law or the equal protection of the laws within the territory of India.” Yet, the NDPS does not distinguish between pure drugs and mixtures. For example, a defendant found guilty of possessing 10 kg of pure opium receives the automatic death penalty just the same as a defendant found guilty of possessing 10 kg of an opium *mixture*. Arguing that the purpose of the ADPS was to punish in accordance with drug quantity, the Petitioner argued that ADPS violated Article 14. The Court disagreed, simply stating that the classification of drugs was “based on intelligible differentia.”

*Proportionality*

The petitioner argued that, since providing or consuming narcotics listed under section 31-A do not directly or indirectly cause loss of life, violations of section 37-A do not constitute the “most serious crimes.” Therefore, since article 6 of the ICCPR provides that the “sentence of death may be imposed only for the most serious crimes[,]” the petitioner argued that the mandatory death penalty for violations of section 31-A were disproportionate to the crime and unconstitutional.

The Court disagreed. According to the Court, the death penalty was based on intelligible differentia and the differentia had a rational nexus to the law’s purpose (i.e. reducing the illicit drug trade and lowering illicit drug consumption). Moreover, the Court found that Indian precedent clearly established that offenses relating to narcotics were more heinous than homicide. Finally, the Court held that the ICCPR did not control when municipal law enacted within the context of the Indian Constitution existed.

**Commentary and Analysis**

In the end, the Court found that the mandatory death penalty for narcotic-related offenses violated article 21 (protection of life and personal liberty) but not article 14 (equal protection of the laws). The death penalty is still possible in courts within the jurisdiction of the High Court at Bombay for those who violate section 31-A, but it is no longer mandatory. It is the trial court judge’s discretion to impose the death penalty after s/he has fairly evaluated each individual defendant and offense.

The constitutions of many countries provide for due process of law, separation of powers or equal protection. In *Mithu*, any one of these constitutional provisions was independently sufficient to read down the mandatory nature of section 31-A from “shall” to “may.” Challenges to similar laws based on similar constitutional measures may very well succeed in other legal venues.

**Lawyers Collective**

New Dehli & Mumbai, India

E-mail New Dehli: [aidslaw1@lawyerscollective.org](mailto:aidslaw1@lawyerscollective.org)

E-mail Mumbai: [aidslaw@lawyerscollective.org](mailto:aidslaw@lawyerscollective.org)

Website: [www.lawyerscollective.org](http://www.lawyerscollective.org)

## Example 8: Encouraging implementation of CESCR recommendations on opioid substitution treatment in Russia

### Project Type

Advocacy and Litigation

### The Organization

The Andrey Rylkov Foundation for Health and Social Justice (ARF) is a non-profit organization incorporated in the Russian Federation in September 2009. The aim of ARF is to develop and promote a “humane drug policy based on tolerance, protection of health, dignity and human rights in Russia.” It is a small organization with a minimalist budget that depends on volunteers for most of its program activities.

### The Problem

Opioid substitution therapy (OST) is an effective method for reducing the harms associated with injection drug use. Yet, Russia prefers to incarcerate people who use drugs instead of providing them with OST. Indeed, Russia prohibits access to OST, disseminates false or misleading information regarding OST, stifles discussion of OST and promotes a treatment for injection drug use that ignores best practices in science. As a result, Russia now faces the world’s largest and most dramatic rise in HIV/AIDS morbidity within its injecting drug use community.

### Actions Taken

ARF has pursued a multifaceted strategy to secure access to OST in Russia, including proceedings before domestic courts, direct appeals to the highest state authorities, and activities to raise public awareness of the need for the measures recommended by the international human rights bodies.

### Alleged Violations

Right to the highest attainable standard of physical and mental health (ICESCR, art. 12; UDHR, art. 25; Russian Const., art. 41).

Right to enjoy the benefits of scientific progress and its application (ICESCR, art. 15(b)).

Right to freedom of information (ICCPR, art. 19; UDHR, art. 19; Russian Const., art. 29(4)).

On April 2, 2010, ARF submitted a shadow report to the International Committee on Economic, Social, and Cultural Rights (CESCR) on Russia’s failure to implement the right to health (art. 12) “as it relates to access of people who inject drugs to drug treatment and HIV prevention, care and treatment programs.”<sup>94</sup> Specifically, ARF presented evidence that the government violated the human rights of people who use drugs by banning access to harm reduction services and information, including OST.

On May 20, 2011, the CESCR issued its Concluding Observations to the Russian Federation, recommending that the government “apply a human rights-based approach to drug users so that that they do not forfeit their basic right to health” and “provide clear legal grounds and other support for the internationally

<sup>94</sup> Report to CESCR on implementation by Russia of ICESCR Article 12 as it relates to access of people who inject drugs to drug treatment and HIV prevention, care and treatment programs ([www2.ohchr.org/english/bodies/CESCR/docs/ngos/fhsj\\_RussianFederation\\_wg44.doc](http://www2.ohchr.org/english/bodies/CESCR/docs/ngos/fhsj_RussianFederation_wg44.doc)) and Supplemental Report ([http://www2.ohchr.org/english/bodies/cescr/docs/ngos/AndreyRylkovFoundation\\_RussianFederation\\_CESCR46.doc](http://www2.ohchr.org/english/bodies/cescr/docs/ngos/AndreyRylkovFoundation_RussianFederation_CESCR46.doc)). See also, Additional information to the Report to CESCR on implementation by Russian of ICESCR Article 12 as it relates to access of people who inject drugs to drug treatment and HIV prevention, care and treatment programs (in response to the replies by the Government of the Russian Federation to the list of issues (E/C.12/RUS/Q/5) to be taken up in connection with the consideration of the fifth periodic report of the Russian Federation (E/C.12/RUS/5) of 9 February 2011). <http://en.rylkov-fond.org/wp-content/uploads/2012/01/AFR-ICESCR-may-5-2011.pdf>.

recognized measures for HIV prevention among injecting drug users, in particular the opioid substitution therapy (OST) with use of methadone and buprenorphine, as well as needle and syringe programs and overdose prevention programs.” (UN Doc. E/C.12/RUS/CO/5)

On September 2, 2011, ARF submitted a formal request to the Office of the President, as guarantor of the Russian Constitution, asking for implementation of the CESCR Recommendations, including the introduction of OST in Russia. The President’s administration forwarded this request to the Ministry of Health, which responded to ARF with false information on the ineffectiveness of OST. ARF did not request information on the efficacy of OST. ARF submitted a new request to the President asking for an appropriate reply. However, the President’s Administration responded that the initial reply would suffice.

On January 10, 2012, ARF submitted a complaint to the district court against the President’s Administration and the Ministry of Health, claiming that both had violated the right to a reply on the merits and the right to receive objective, accurate information about the affairs of the state bodies. In July 2012, the district court dismissed the complaint based on the constitutional provision of separation of powers. According to the district court, the court cannot pass judgment mandating the President’s Administration to propose certain laws. ARF did not request the court to pass judgment; it requested the court to mandate the Administration to fulfill its obligations to reply to citizens on the merits of their petitions. An appeal was filed in July 2012 to the Moscow City Court and on October 2, 2012, the court of appeal upheld the judgment of the district court. ARF is preparing an application to the UN Human Rights Committee claiming the violation of the right to receive reliable information on the matters related to the implementation of the International Covenants on Human Rights.<sup>95</sup>

### Results and Lessons Learned

The work of ARF demonstrates successful advocacy for OST and other harm reduction services on an international level. Nevertheless, Russia continues to void its international treaty obligations and has in fact retaliated against ARF by persecuting its staff for challenging the legal ban on OST. On February 3, 2011, it shut down the entire ARF website.<sup>96</sup> ARF continues its advocacy work at the domestic level through court-based challenges, calls for changes to domestic drug-related legislation and policies, calls for international attention to ARF website closure, and ongoing recommendations on further actions to protect the human rights violations of people who use drugs.

#### Andrey Rylkov Foundation for Health and Social Justice

E-mail: [Rylkov.foundation@gmail.com](mailto:Rylkov.foundation@gmail.com)

Website: <http://en.rylkov-fond.org/> (English)

<sup>95</sup> See ARF-CALN Submission for the Human Rights Council’s Periodic Review of the Russian Federation (2012). <http://en.rylkov-fond.org/blog/arf-advocacy/arf-international-advocacy/submission-hrc-2012/>.

<sup>96</sup> See also, Information note regarding retaliation of the Government of the Russian Federation against ARF for promoting the recommendations made by the UN CESCR to the Russian Federation in its Concluding Observations (Feb. 14, 2012). <http://en.rylkov-fond.org/blog/arf-advocacy/arf-international-advocacy/infonote-cescr-arf-website/>.

## Example 9: Methadone maintenance treatment in Alberta prisons

*Milton Cardinal v. The Director of the Edmonton Remand Centre and the Director of the Fort Saskatchewan Correctional Centre*

### Project Type

Litigation

### Organization

This is an example of an individual bringing an action to challenge a human rights abuse.

### The Problem

Milton Cardinal was addicted to opiate-based narcotics for over 20 years when, in 2002, he applied for and received methadone maintenance treatment (MMT) through the Alberta Alcohol and Drug Abuse Commission (AADAC). In 2002, Mr. Cardinal was arrested and held in the Edmonton Remand Centre (ERC). It was the policy of the ERC to permit those already receiving MMT therapy to continue to receive MMT from the AADAC for 30 days, at which point the prisoner would be placed on “mandatory withdrawal.” Unsurprisingly, when Mr. Cardinal was placed on mandatory withdrawal, he experienced acute physical and mental pain as a result of the prison’s policy.

### Arguments and Holdings

The court never issued a judgment in this case. Since filing the action prompted the government to change its policy and allow Mr. Cardinal and others similarly situated to receive MMT, the case became moot.

### Commentary and Analysis

Mr. Cardinal brought a civil action against the ERC, arguing that withholding his MMT amounted to a violation of his rights under Sections 7, 12, and 15 of the Canadian Charter of Rights and Freedoms. Before the case could go to trial, a change in policy allowed prisoners in Alberta, like Mr. Cardinal, to receive MMT while in jail. The case settled with the two parties agreeing, “The provision of methadone maintenance treatment to persons who suffer from opioid drug addiction constitutes the community standard of health care in the province of Alberta.”

## Canadian Charter of Rights and Freedoms

s. 7 Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

s. 12 Everyone has the right not to be subjected to any cruel and unusual treatment or punishment.

s. 15(1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.



MMT therapy, particularly for prisoners, is an important element of any harm reduction program. Prisoners require MMT while in prison and referrals to community-based MMT programs prior to their release. Beyond the individual health benefits to the prisoners, MMT benefits the community by driving lower recidivism rates. Unfortunately, clear practical obstacles exist to establishing an effective MMT program, including the stigmas associated with pharmacological treatment, misconceptions regarding the nature of opioid addiction, logistics of control and storage of methadone, increased work load for nursing staff and general safety and control concerns. Therefore, an effective legal strategy, built on existing rights, may be the best way to leverage and pry open MMT programs for prisoners who need them.

“That [denial of MMT] was wrong . . . . They have no right to torture your client, none whatsoever. It’s almost like keeping food away from him, starving him. He needs this. It’s a medical necessity. He’s going to get it.” –**Justice Feehan, Alberta Court of Queen’s Bench**

## 5. HOW CAN I FIND ADDITIONAL RESOURCES ABOUT HARM REDUCTION AND HUMAN RIGHTS?

A list of commonly used resources on harm reduction and human rights follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Declarations & Statements
- D. Harm Reduction Generally
- E. Human Rights & Harm Reduction – General
- F. Right to Life
- G. Freedom from Torture and Cruel, Inhuman and Degrading Treatment
- H. Freedom from Arbitrary Arrest and Detention
- I. Right to a Fair Trial
- J. Right to Privacy
- K. Right to Non-Discrimination
- L. Right to Health
- M. Right to an Adequate Standard of Living and Right to Work
- N. Women
- O. Children
- P. Key Populations – HIV/AIDS, TB or Hepatitis
- Q. Key Populations – Prisoners
- R. Key Populations – Sex Workers
- S. Key Populations – LGBTQ & MSM
- T. Advocacy, Training and Programming Materials
- U. Periodicals
- V. Websites

## A. International Instruments

### Nonbinding

- UN Committee on the Rights of the Child, *General Comment No. 3: HIV/AIDS and the Rights of the Child*, CRC/GC/2003/3 (March 17, 2003). [www2.ohchr.org/english/bodies/crc/comments.htm](http://www2.ohchr.org/english/bodies/crc/comments.htm).
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## 6. WHAT ARE KEY TERMS RELATED TO HARM REDUCTION AND HUMAN RIGHTS?

### A

#### **Addiction**

A commonly used term that describes a pattern of drug use indicating physical or mental dependence. It is not a diagnostic term and is no longer used by the World Health Organization (WHO).

#### **Advocacy**

Harm reduction efforts often include an advocacy component, which may involve lobbying for drug users' rights, or for funding for harm reduction programs, or trying to change public perception of drug users and of harm reduction.

#### **AIDS**

Acquired Immunodeficiency Syndrome (AIDS) is the severe manifestation of infection with the Human Immunodeficiency Virus (HIV).

#### **Alcohol pad**

A small piece of fabric soaked with alcohol, used to swab the skin before injecting. (Washing with soap and water is thought to be more effective at reducing infection than rubbing with an alcohol pad. Cleaning hands and potential sites of injection also reduces the potential for infection.)

#### **Amphetamine-type stimulants**

Refers to a group of drugs including amphetamine (also referred to as speed), methamphetamine, methcathinone, fenetylline, ephedrine, pseudoephedrine, methylphenidate, and MDMA (also called ecstasy – an amphetamine-type derivative with hallucinogenic properties). Amphetamine-type stimulants cause increased wakefulness and focus; use is increasing worldwide.

#### **Anti-Retroviral Therapy (ART)**

Anti-retroviral drugs inhibit various phases of the life-cycle of the human immunodeficiency virus (HIV), thus reducing HIV-related symptoms and prolonging life expectancy of people living with HIV.

### B

#### **Backloading and frontloading**

“Backloading” and “frontloading” refer to a practice whereby one syringe is used to prepare the drug solution, which is then divided into one or more syringes for injection. The drug solution is shifted from one syringe into another with the needle (frontloading) or plunger (backloading) removed. HIV, hepatitis, and other infectious agents can be transmitted if the preparation syringe has been contaminated.

#### **Biohazard containers**

Puncture-resistant containers used for disposing of hazardous waste such as used syringes. The contents of biohazard containers are disposed of at a location specifically designed to negate the potential dangers of hazardous waste. The containers are ideally designed so that hazardous material cannot be removed once it is placed into the container.

***Buprenorphine***

A medication used in substitution therapy programs. Buprenorphine is included in the World Health Organization (WHO) Model List of Essential Medicines. See also

***Buprenorphine Maintenance Treatment***

See Substitution or replacement therapy.

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**C*****Community-based outreach programs***

These programs are an effective way to provide information and outreach services to drug users with the goal of prevention and health promotion.

***Consumption rooms***

Safe, clean places for drug users to inject sterilely and under medical supervision. Information, sterile injection equipment, and health services are often provided.

***Cooker***

Any item used to heat injectable drugs in order to turn them from powder or other non-liquid form into a liquid suitable for injection. (According to some experts, injection drug users often reused metal spoons for cooking drugs until harm reduction service providers began promoting the one-time use of disposable items, such as bottle caps or similarly shaped objects, in order to reduce the risk of disease transmission.)

***Cotton***

Any item used to filter out particles of solids from injectable liquid drugs, in order to prevent them from clogging syringes. From the point of view of sterile injection, the ideal filter is a sterilized cotton pellet, made of natural cotton fibers and especially cut for this purpose.

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**D*****Decriminalization***

Unlike legalization, decriminalization refers only to the removal of penal and criminal sanctions on an activity, which retains prohibited status and non-penal regulation.

***Demand reduction***

Programs and policies aimed at directly reducing demand for illicit drugs via education, treatment, and rehabilitation, without reliance on law enforcement or prevention of production and distribution of drugs.

***Drop-in centre***

Centers provide easy-to-access basic care and information to drug users.

***Drug consumption rooms***

Drug consumption rooms are medically supervised sites that provide a safe and hygienic site for consumption of illicit drugs. The sites often provide sterile injection equipment as well as information about drugs and medical and treatment referrals. Some sites may offer additional medical or counselling services.

***Drug policy***

Refers to the sum total of policies and laws affecting supply and/or demand of illicit drugs, and may include issues such as education, treatment, and law enforcement.

**Drug use**

Preferred term for use in harm reduction context, acknowledging that drug use is a nearly universal cultural behavior with a wide range of characteristics and impacts, depending on the individual user.

**Drug-related harms**

Include HIV and AIDS, other viral and bacterial infections, overdose, crime, and other negative consequences stemming from drug use and from policies and problems relating to drug use.

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**H****Harm reduction**

Refers to a set of interventions designed to diminish the individual and societal harms associated with drug use, including the risk of HIV infection, without requiring the cessation of drug use. In practice, harm reduction programs include syringe exchange, drug substitution or replacement therapy using substances such as methadone, health and drug education, HIV and sexually transmitted disease screening, psychological counseling, and medical care.

**Hepatitis B and C**

Hepatitis B and C are blood borne diseases causing inflammation of the liver. Hepatitis B and C can be contracted through sharing needles and hepatitis B can also be spread through unprotected sex.

**Heroin**

An illegal narcotic whose use is rare compared to the use of other drugs, but which has been viewed in many areas as a social scourge dangerous to health and related to criminality.

**Heroin-assisted treatment**

Refers to the prescription and use of medical heroin for heroin or opiate users. Heroin-assisted treatment is proven as effective treatment and is currently utilized as a second-line treatment for users who failed to respond to opioid replacement therapy using methadone or buprenorphine.

**HIV**

The Human Immunodeficiency Virus (HIV) attacks and weakens the immune system. HIV infection eventually leads to AIDS, but proper medical treatment can delay symptoms for years.

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**I****Injection equipment**

Items such as syringes, cottons, cookers, and water used in the process of preparing and injecting drugs. Each of these can be contaminated and transmit HIV or hepatitis. The broader term “drug paraphernalia” comprises injection equipment, as well as items associated with non-injection drug use, such as crack pipes.

**Injecting drug use**

Refers to the consumption of a drug through injection into the body by use of a needle or syringe.

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**L****Legalization**

As opposed to decriminalization, legalization refers to the process of transferring an activity from prohibited status to legally controlled status.

**M*****Methadone***

A medication used in opioid substitution therapy programs. It is included in the WHO Model List of Essential Medicines.

***Methadone maintenance treatment***

See Substitution or replacement therapy.

***Methamphetamines***

A group of substances, most of them synthetic, that have a stimulating effect on the central nervous system. Methamphetamines can be injected, snorted, smoked, or ingested orally. The popular term “crystal meth” usually refers to the smokeable form of methamphetamine. Other amphetamine-type stimulants include anoretics (appetite suppressants) and non-hallucinogenic drugs such as “ecstasy.”

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**N*****Needle or syringe exchange points***

Programs that provide sterile syringes in exchange for used ones. In addition to exchanging syringes, needle exchange points often provide HIV prevention information and screening, primary health care, and referrals to drug treatment and other health and social services.

***Needle sharing***

The use by more than one person of the same needle, or, more generally, of the same injecting or drug-preparation equipment. It is a common route of transmission for blood-borne viruses and bacteria, and the prevention of needle sharing is a major focus for many harm reduction interventions.

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**O*****Opioid substitution therapy***

See Substitution or replacement therapy.

***Overdose prevention***

Overdosing is a significant cause of morbidity and mortality among drug users, and is a major focus of harm reduction initiatives, including outreach, health services, safe injection rooms, and access to information on how to reduce the likelihood of an overdose.

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**R*****Risk behavior reduction***

Behaviors that place drug users at risk of adverse consequences are a main focus of a set of harm reduction initiatives referred to as risk reduction for their focus on reducing the risk of drug-related harm.

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**S*****Safe injection facility***

See Drug consumption room.

***Sex worker***

A non-judgmental term which avoids negative connotations and recognizes that people sell their bodies as a means of survival, or to earn a living. (UNAIDS)

**Shirka**

The popular name for one of the most commonly injected opiate derivatives used in Ukraine, a homemade preparation of acetylated or extracted opium. In the Odessa region, shirka refers to a homemade amphetamine derivative known elsewhere in the country as vint or perventin.

**Substance abuse**

A widely-used but poorly defined term that generally refers to a pattern of substance use that results in social or health problems, and may also refer to any use of illegal drugs.

**Substitution or replacement therapy**

Medically supervised administration of a psychoactive substance pharmacologically related to the one creating dependence (often buprenorphine or methadone) to substitute for that substance. This aims at preventing withdrawal symptoms while reducing or eliminating the need or desire for illicit drugs. Substitution therapy seeks to assist drug users in switching from illicit drugs of unknown potency, quality, and purity to legal drugs obtained from health service providers or other legal channels, thus reducing the risk of overdose and HIV risk behaviors, as well as the need to commit crimes to obtain drugs.

**Syringes or needles**

The main components of a syringe are a needle, a tubular syringe barrel, and a plastic plunger. Graduated markings on the barrel of a syringe are used to measure the water or saline solution used to dissolve a solid substance into liquid form. Syringes and needles vary in size and do not always come as one piece; a syringe with the needle attached is often referred to as an “insulin syringe.” While disinfection of syringes is possible, public health authorities recommend a new sterile syringe for every injection.

**T****Ties or tourniquets**

Items used to enlarge or “plump up” veins to facilitate injection. Ties should be clean because blood on a tie can be a source of infection. Common ties include a piece of rope, a leather belt, a terry cloth belt, a rubber hose, and a piece of bicycle inner tube.

**V****Vint or perventin**

The popular names for an injected homemade amphetamine derivative. (See Shirka.)

**W****Water**

Water is used to dissolve solid substances (such as pills or powder) into a liquid form suitable for injection. Having a clean source of one’s own water is important to prevent disease transmission. Harm reduction programs often distribute vials of distilled water, sterile water or sterile saline solution (all referred to as “waters”) for this purpose.

**Withdrawal**

Clinical symptoms associated with ceasing or reducing use of a chemical agent that affects the mind or mental processes (i.e., a “psychoactive” substance). Withdrawal usually occurs when a psychoactive substance has been taken repeatedly and/or in high doses.

# CHAPTER 5



## PALLIATIVE CARE AND HUMAN RIGHTS

“ You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die. ”

— Dame Cicely Saunders, founder of the modern hospice movement

## **Health and Human Rights Resource Guide**

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Cover photograph courtesy of Sven Torfinn – Panos, Open Society Foundations, “Mercy visits Charles, a cancer patient. She sees him every week, bringing pain medication and providing him with emotional support”

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# INTRODUCTION

This chapter will introduce you to key issues in palliative care and human rights. The chapter is organized into six sections that answer the following questions:

1. How is palliative care a human rights issue?
2. What are the most relevant international and regional human rights standards related to palliative care?
3. What is a human rights-based approach to advocacy, litigation, and programming?
4. What are some examples of effective human rights-based work in the area of palliative care?
5. Where can I find additional resources on palliative care and human rights?
6. What are key terms related to palliative care and human rights?

# I. HOW IS PALLIATIVE CARE A HUMAN RIGHTS ISSUE?

## What is palliative care?

“Palliative care is an approach that seeks to improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering.”<sup>1</sup> It also addresses the psychosocial, legal, and spiritual aspects associated with life-threatening illnesses.<sup>2</sup>

Palliative care is fundamental to health and human dignity and is a basic human right.<sup>3</sup> The United Nations Committee on Economic, Social and Cultural Rights asserted that “States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services.”<sup>4</sup> The United Nations Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment stated that he “is of the opinion that the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment.”<sup>5</sup>

Palliative care should be provided from the time of diagnosis and in tandem with any curative treatment. As the patient’s disease progresses into the terminal phase, palliative care should adapt to the patient’s changing needs. Palliative care must include psychological and spiritual services and other support in preparation for death. Palliative care programs should also tend to the needs of the family throughout the progression of the disease and into bereavement.<sup>6</sup> Some programs include legal services to address power of attorney or health care proxy decisions and assistance in executing a will.

Palliative care programs are most effective when integrated into existing health care systems and at all levels of care. Programs can be designed to be provided in hospital or clinic settings, as well as the patient’s home or residential facility (such as a nursing home). Ideally, palliative programs overlap in providing care at all levels. Palliative care programs involve both the public and private sector, and can be adapted to the specific cultural, economic, and social setting.<sup>7</sup>

<sup>1</sup> UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

<sup>2</sup> Open Society Foundations, *Palliative Care as a Human Right* (2011). [www.soros.org/sites/default/files/palliative-care-human-right-20110524.pdf](http://www.soros.org/sites/default/files/palliative-care-human-right-20110524.pdf).

<sup>3</sup> Ibid.

<sup>4</sup> UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, E/C.12/2000/4, para. 34 (Aug. 11, 2000).

<sup>5</sup> UN Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/10/44, para. 72 (Jan. 14, 2009).

<sup>6</sup> World Health Organization, *Cancer Control Knowledge into Action: WHO Guide for Effective Programs* (2007). [http://whqlibdoc.who.int/publications/2007/9241547345\\_eng.pdf](http://whqlibdoc.who.int/publications/2007/9241547345_eng.pdf).

<sup>7</sup> Ibid.

## World Health Organization Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

## How is palliative care a human rights issue?

The need for palliative care worldwide is great. Of the 58 million people dying annually, at least 60% will have a prolonged advanced illness and would benefit from palliative care. About 80% of the dying would benefit from palliative care to alleviate pain and suffering in their final days. Unfortunately for many, palliative care programs are either unavailable or are inaccessible. The United Nations Special Rapporteur on the highest attainable standard of mental and physical health (Special Rapporteur on the Right to Health) noted that “[p]atients suffering from severe to moderate pain, where palliative care essentially is unavailable, said they would prefer to die than continue living with untreated, severe pain.”<sup>8</sup>

Palliative care should be available for anyone suffering from moderate or severe pain, but below we highlight cancer and AIDs patients because of the overwhelming need for palliative care among these populations, as well as older persons and children, for whom palliative care is often an afterthought.

### Cancer patients

Cancer patients are one the largest populations in need of palliative care. The World Health Organization (WHO) projects that global cancer deaths will increase from 7.9 million in 2007 to 11.5 million in 2030.<sup>9</sup> In addition, new cases of cancer during the same period are estimated to grow to 15.5 million in 2030, up from 11.3 million in 2007.<sup>10</sup> Over half of the new cancer cases each year occur in less developed countries.<sup>11</sup> And while the WHO has demonstrated that up to 90% of cancer patients can receive adequate therapy for their pain with opioid analgesics, in 2005, 80% of cancer patients did not have access to pain relieving drugs.

<sup>8</sup> UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

<sup>9</sup> World Health Organization, *Are the number of cancer cases increasing or decreasing in the world* (Apr. 1, 2008). [www.who.int/features/qa/15/en/index.html](http://www.who.int/features/qa/15/en/index.html).

<sup>10</sup> Ibid.

<sup>11</sup> World Health Organization, *National Cancer Control Programmes: Policies and Managerial Guidelines* (2002). <http://whqlibdoc.who.int/hq/2002/9241545577.pdf>.

Pain associated with cancer can be unbearable. Pain can be caused by the cancer itself, a cause related to the cancer, a consequence caused by or related to the cancer treatment, or by a concurrent disorder.<sup>12</sup> To guide policy makers and health care practitioners, the WHO developed the “pain-relief ladder,” a simple three-phase guide on pain relief for people suffering from cancer.<sup>13</sup> WHO also recommends treatment for the psychological suffering of cancer patients including for anxiety and depression. WHO writes, “The aim of treatment is to relieve the pain to the patient’s satisfaction, so that he or she can function effectively and eventually die free of pain.”<sup>14</sup>

## People living with HIV and AIDS

There are approximately 34.2 million people living with HIV and an estimated 1.7 million AIDS-related deaths each year.<sup>15</sup> Up to 80% of patients in the advanced stages of AIDS suffer great pain, but very few have access to pain relieving drugs or palliative care services. The Special Rapporteur on the Right to Health estimates that around 85% of people living with HIV may have untreated pain.<sup>16</sup> Again, less developed countries experience the highest rates of HIV/AIDS infection, but have limited access to opioid medications for pain relief.

Palliative care for people living with AIDS has its own challenges. The progression of AIDS is variable and unpredictable, and people experience a wide range of complications and rates of survival.<sup>17</sup> People with AIDS face possible opportunistic infections as well as experience different side effects from treatment for the infections and AIDS itself.<sup>18</sup> Providing palliative care for people with AIDS must adjust to the differing needs of patients. People with HIV/AIDS also experience discrimination and stigma, influencing the individual’s access to health care, living experiences, and personal support networks. For example, “Where patients with HIV are also dependent on drugs, they may be denied access to both OST and palliative care.”<sup>19</sup> Designers of palliative care programs should be cognizant of the additional social pressures and lack of services that AIDS patients face.

## Older persons

The United Nations Committee on Economic, Social and Cultural Rights states that, with regard to the realization of the right to health of older persons, “attention and care for chronically and terminally ill persons [is important], sparing them avoidable pain and enabling them to die with dignity.”<sup>20</sup> Older persons experience increased rates of chronic and terminal illnesses, and therefore are a significant portion of the population that requires palliative care. There are about 605 million people aged 60 years and over, and WHO expects that number to increase to 2 billion by 2050, with low- and middle-income countries experiencing the most rapid changes.<sup>21</sup> As the older population grows in size, palliative care programs will have to be developed or augmented to address their specific needs.

<sup>12</sup> World Health Organization, *Cancer Pain Relief: With a guide to opioid availability* (1996): 5. <http://whqlibdoc.who.int/publications/9241544821.pdf>.

<sup>13</sup> World Health Organization, “WHO’s Pain Ladder.” [www.who.int/cancer/palliative/painladder/en/](http://www.who.int/cancer/palliative/painladder/en/). For a more detailed analysis see, WHO, *Cancer Pain Relief: With a guide to opioid availability* (1996). <http://whqlibdoc.who.int/publications/9241544821.pdf>.

<sup>14</sup> World Health Organization, *Cancer Pain Relief: With a guide to opioid availability* (1996): 3. <http://whqlibdoc.who.int/publications/9241544821.pdf>.

<sup>15</sup> UNAIDS, *Global AIDS epidemic facts and figures, Fact Sheet* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

<sup>16</sup> UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

<sup>17</sup> UNAIDS, *AIDS: Palliative Care* (Oct. 2000): 3. [http://data.unaids.org/Publications/IRC-pub05/JC453-PalliCare-TU\\_en.pdf](http://data.unaids.org/Publications/IRC-pub05/JC453-PalliCare-TU_en.pdf).

<sup>18</sup> Ibid.

<sup>19</sup> UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

<sup>20</sup> UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, E/C.12/2000/4, para. 25 (Aug. 11, 2000).

<sup>21</sup> World Health Organization, “Ageing and Life Course: Interesting Facts About Ageing” (Mar. 28, 2010). [www.who.int/ageing/about/facts/en/index.html](http://www.who.int/ageing/about/facts/en/index.html).

Palliative care programs must not discriminate against people based on their age. The Special Rapporteur on the Right to Health notes that while barriers to palliative care are not unique to older persons as a group, they are “disproportionately affected due to the increased incidence of chronic and terminal illness amongst them.”<sup>22</sup> The Special Rapporteur also queried whether older persons are less likely to receive palliative care, noting that more research is required to determine whether the distribution of palliative care services are “inequitable or whether the needs of older persons are being met through other services.”<sup>23</sup>

## Children<sup>24</sup>

Children with terminal illnesses and debilitating diseases suffer from pain but are often not provided with palliative care. Children’s pain is often underestimated or even neglected because of cultural beliefs or ignorance. The International Children’s Palliative Care Network estimated that 20 million children worldwide can benefit from palliative care.<sup>25</sup> Children suffer from terminal illnesses like cancer and AIDS, as well as debilitating disabilities. For example, in 2008, the American Cancer Society estimated that 175,300 new cases of cancer occurred, and 96,400 children died from the disease.<sup>26</sup> In 2011, an estimated 3.4 million children were living with HIV/AIDS and 330,000 children were newly infected.<sup>27</sup>

Palliative care seeks to improve the quality of life for a patient. “For children this also includes support of optimal childhood development, formal education, and developmental stimulation to enable the child, at every age, to live the best life possible.”<sup>28</sup> At all times, the best interest of the child must be the primary consideration.

## Access to essential medicines

An important component of palliative care is access to essential drugs to alleviate pain. For many with terminal illnesses, pain and suffering caused by the illness is debilitating but can be easily treated with opioid analgesics. The International Narcotics Control Board reported that, in 2009, more than 90% of the global consumption of opioid analgesics occurred in Australia, Canada, New Zealand, the United States of America, and several European countries.<sup>29</sup> Consequently, over 80% of the world has insufficient or no access to opioid medications, and therefore have no relief from their pain and suffering.<sup>30</sup>

22 UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Thematic Study, A/HRC/18/37 (July 4, 2011). [http://www2.ohchr.org/english/bodies/hrcouncil/docs/18session/A-HRC-18-37\\_en.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/docs/18session/A-HRC-18-37_en.pdf).

23 Ibid.

24 For technical guidance on pharmacological treatment of children and policy reform recommendations, please see World Health Organization, *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses* (2012). [http://whqlibdoc.who.int/publications/2012/9789241548120\\_Guidelines.pdf](http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf); World Health Organization, *Persisting Pain in Children: Highlights for policy makers* (2012). [http://whqlibdoc.who.int/publications/2012/9789241548120\\_%20Policy%20Brochure.pdf](http://whqlibdoc.who.int/publications/2012/9789241548120_%20Policy%20Brochure.pdf); World Health Organization, *Persisting Pain in Children: Highlights for physicians and nurses* (2012). [http://whqlibdoc.who.int/publications/2012/9789241548120\\_Physicians&Nurses.pdf](http://whqlibdoc.who.int/publications/2012/9789241548120_Physicians&Nurses.pdf); World Health Organization, *Persisting Pain in Children: Highlights for pharmacists* (2012). [http://whqlibdoc.who.int/publications/2012/9789241548120\\_Pharmacists\\_Brochure.pdf](http://whqlibdoc.who.int/publications/2012/9789241548120_Pharmacists_Brochure.pdf).

25 International Children’s Palliative Care Network, “The need for Children’s Palliative Care.” [www.icpcn.org.uk/page.asp?section=0001000100080002](http://www.icpcn.org.uk/page.asp?section=0001000100080002).

26 American Cancer Society, *Global Cancer Facts and Figures* (2008). [www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-027766.pdf](http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-027766.pdf).

27 UNAIDS, *Global AIDS epidemic facts and figures, Fact Sheet* (July 18, 2012). [www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207\\_FactSheet\\_Global\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/201207_FactSheet_Global_en.pdf).

28 Hospice Palliative Care Association of South Africa, “Chapter 8: Legal Rights of Children in Palliative Care,” in *Legal Aspects of Palliative Care Manual* (2012). [www.hpca.co.za/Legal\\_Resources.html](http://www.hpca.co.za/Legal_Resources.html).

29 International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). [http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/ife/Report\\_of\\_the\\_Board\\_on\\_the\\_availability\\_of\\_controlled\\_substances.pdf](http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/ife/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf).

30 Ibid.



Manfred Nowak, UN Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, and Anand Grover, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, stated:

*Governments also have an obligation to take measures to protect people under their jurisdiction from inhuman and degrading treatment. Failure of governments to take reasonable measures to ensure accessibility of pain treatment, which leaves millions of people to suffer needlessly from severe and often prolonged pain, raises questions whether they have adequately discharged this obligation.<sup>31</sup>*

### Essential medicines

WHO has developed two lists of medicines that it considers essential for satisfying the priority health care needs of the population. They are called the Model List of Essential Medicines and the Model List of Essential Medicines for Children,<sup>32</sup> and they serve as a guide for national and institutional essential medicines lists.<sup>33</sup> The Committee on Economic, Social and Cultural Rights established in General Comment 14 that states are obligated to provide “essential medicines as defined by the WHO Action Programme on Essential Drugs” as part of the minimum core obligations to realize the right to health.<sup>34</sup>

In 2007, the International Association for Hospice and Palliative Care (IAHPC), in collaboration with 26 palliative care organizations, developed a list of essential medicines for palliative care.<sup>35</sup> Of the 34 medications listed, just 14 were included in the WHO Model List (most recently updated in 2011), and morphine is the only strong opioid analgesic on the WHO list. Oral morphine is particularly essential for palliative care because it provides an inexpensive option for pain management. However, especially in low- and middle-low income countries, opioid formulations that are more expensive or more difficult to use, such as injectable morphine, are only available. The high cost of these opioids hinders access to treatment. Meanwhile, the low profit margin from oral morphine is exacerbated by additional costs of unnecessarily burdensome regulatory requirements, which may further deter the pharmaceutical industry from supplying it.<sup>36</sup>

### International drug control conventions

Many essential medicines identified by the WHO are controlled medicines under international drug control conventions, including the Single Convention on Narcotic Drugs (1961) amended by the 1972 Protocol; the Convention on Psychotropic Substances (1971); and the United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances (1988). These medicines are controlled because of their addictive properties and likelihood for misuse.

31 Joint letter by UN special rapporteur on the prevention of torture and cruel, inhuman or degrading treatment or punishment, Manfred Nowak, and the UN special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, to the Commission on Narcotic Drugs (December 2008). <http://www.hrw.org/news/2008/12/10/un-human-rights-experts-call-upon-cnd-support-harm-reduction>.

32 World Health Organization, *Medicines: WHO Model Lists of Essential Medicines* (March 2011). [www.who.int/medicines/publications/essentialmedicines/en/](http://www.who.int/medicines/publications/essentialmedicines/en/).

33 World Health Organization, “Medicines: Essential Medicines.” [www.who.int/medicines/services/essmedicines\\_def/en/index.html](http://www.who.int/medicines/services/essmedicines_def/en/index.html).

34 UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14* (2000), E/C.12/2000/4 (Aug. 11, 2000).

35 International Association for Hospice and Palliative Care, *IAHPC List of Essential Medicines for Palliative Care* (2007). <http://hospicecare.com/resources/palliative-care-essentials/iahpc-essential-medicines-for-palliative-care/>.

36 Pallium India, “The Morphine Manifesto” (2012). <http://palliumindia.org/manifesto/>.

The International Narcotics Control Board (INCB) oversees the distribution of controlled substances, as designated by the international drug control conventions. The INCB states:

*The international drug control treaties recognize that narcotic drugs and psychotropic substances are indispensable for medical and scientific purposes. However, despite numerous efforts by the Board and the World Health Organization (WHO), as well as non-governmental organizations, their availability in much of the world remains very limited, depriving many patients of essential medicines.<sup>37</sup>*

It is the position of the INCB that the international drug control treaties do not prohibit the production and access to controlled substances for medicinal purposes.

## Barriers to accessing essential medicines

So what are the barriers to accessing essential medicines in the majority of the world? The INCB surveyed countries, and determined the main factors affecting the availability of opioids for medical needs: concerns about addiction, reluctance to prescribe or stock controlled substances, insufficient training for professionals, law restricting activities, administrative burden, cost, difficulties in distribution, insufficient supply, and absence of policy.<sup>38</sup>

### Attitude and knowledge-related impediments

Health care professionals are worried about patient addiction to or dependence on opioids and therefore under-prescribe opioids for palliative care purposes. However, studies have demonstrated that prescribing opioids for pain relief does not lead to dependence.<sup>39</sup> “Many myths exist surrounding the use of controlled drugs: that they lead to addiction, do not treat pain adequately, or that chronic or terminal pain is untreatable.”<sup>40</sup> In part, under-prescribing is due to insufficient training for health care professionals. Without proper training, health care workers may be hesitant to prescribe or stock opioids for fear of legal implications, misunderstanding of its efficacy, or fear of addiction.<sup>41</sup> The top three factors listed in the survey responses all correspond to knowledge and attitudinal barriers affecting the availability of opioids for medical purposes.

<sup>37</sup> International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). [http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/life/Report\\_of\\_the\\_Board\\_on\\_the\\_availability\\_of\\_controlled\\_substances.pdf](http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/life/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf).

<sup>38</sup> Ibid.

<sup>39</sup> UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

<sup>40</sup> Ibid.

<sup>41</sup> International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). [http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/life/Report\\_of\\_the\\_Board\\_on\\_the\\_availability\\_of\\_controlled\\_substances.pdf](http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/life/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf); UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

### Laws and regulations

National and local laws and regulations can be so burdensome that they impede the distribution of controlled substances or prohibit their use altogether.<sup>42</sup> For example, “Regulations [may] also limit the substances a doctor may prescribe, or the amount that can be prescribed. Certain States require health-care workers to obtain special licences to prescribe morphine, in addition to their professional licences.”<sup>43</sup> Some countries regulate licensing of controlled medicines to health care institutions, allowing only “Level 1” hospitals to prescribe opioids.<sup>44</sup> In order to determine barriers to accessing essential medicines, States should examine all levels of laws and regulations for the “production, procurement, storage, distribution, prescription, dispensing and administration of opioid analgesics (and other controlled medicines).”<sup>45</sup>

### Cost

Palliative care and access to opioids are frequently promoted as a low-cost solution to pain and suffering. However, access to medicines, even if manufactured at low cost, may not be affordable for all individuals suffering from chronic illnesses. The Special Rapporteur to health explains:

*Despite this, even medicines that can be manufactured at low cost are not necessarily affordable for consumers, because drug producers incur significant regulatory costs that are passed on to consumers within the market price of the drug. For instance, Cipla, a generic manufacturer in India produces 10 mg morphine tablets sold wholesale for US\$ 0.017 each, yet the median cost of a month’s supply of morphine in low- and middle-income countries is \$112, as compared to \$53 for industrialized countries.*<sup>46</sup>

42 International Narcotics Control Board, *Report of the International Narcotics Control Board on the Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes* (2010). [http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/jife/Report\\_of\\_the\\_Board\\_on\\_the\\_availability\\_of\\_controlled\\_substances.pdf](http://www.unodc.org/documents/southerncone/noticias/2011/03-marco/jife/Report_of_the_Board_on_the_availability_of_controlled_substances.pdf).

43 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

44 Ibid.

45 World Health Organization, *Persisting Pain in Children: Highlights for policy makers extracted from the guidelines on the pharmacological treatment of persisting pain in children with medical illnesses* (2012). [http://whqlibdoc.who.int/publications/2012/9789241548120\\_%20Policy%20Brochure.pdf](http://whqlibdoc.who.int/publications/2012/9789241548120_%20Policy%20Brochure.pdf).

46 UN General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/65/255 (Aug. 6, 2010).

## What are current practices in the area of palliative care?

Palliative care includes some or all of the following practices:

- relief from pain;
- symptom control for physical and psychological symptoms;
- essential drugs for palliative care;
- spiritual and bereavement care;
- family-centered care;
- care by trained palliative care professionals;
- home-based care when dying and to die at home if desired;
- treatment of disease and to have treatment withheld or withdrawn;
- information about diagnosis, prognosis, and palliative care services;
- ability to designate a health care proxy for decision making and assistance with the process;
- equitable access to care and provision of services (i.e. no discrimination based on age, gender, socioeconomic status, geographic location, national status, prognosis, or means of infection);
- support system to help patients live as actively as possible until death;
- legal services to assist with estate, property, child custody and care, guardianship, power of attorney or other legal services required by the patient;
- support system to help family cope during the patient's illness and in their own bereavement; and
- services to address the needs of patients and their families, including bereavement counseling.

## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO PALLIATIVE CARE?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to palliative care. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<p><b>UN treaty body interpretation</b></p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
<b>Human rights standards</b>	<p><b>Case law</b></p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and palliative care.

## Abbreviations

In the tables, we use the following abbreviations to refer to the twelve treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment ( <b>CAT</b> )	Committee against Torture ( <b>CAT Committee</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)
Life	Art. 3	Art. 6.1				Art. 6.1
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24
Expression and Information	Art. 19	Art. 19(2)				Art. 13,
Art. 17						
Non-discrimination and Equality	Art. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

**Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADDDM	Americas: ACHR
Torture or Cruel, Inhuman or Degrading Treatment	Art. 5	Art. 3			Art. 5(2)
Life	Art. 4	Art. 2		Art. I	Art. 4
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Non-Discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)



## Table I: Palliative care and freedom from torture and cruel, inhuman, and degrading treatment

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain.</li> <li>Fearing prosecution by the state, a doctor refuses to prescribe morphine to relieve a patient's pain.</li> <li>A country's laws prohibit the prescription of morphine to former drug users. A former drug user is in the advanced stages of AIDS and suffers a great deal.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<b>ICCPR 7:</b> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.	None.

Human Rights Standards	Case Law
<b>ECHR 3:</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.	<b>ECTHR:</b> Finding continued detention of a cancer sufferer where it caused "particularly acute hardship" constituted cruel, inhuman or degrading treatment. <i>Mouisel v. France</i> , 67263/01 (November 14, 2002).

### Other Interpretations

**SR on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment:** "The de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment." A/HRC/10/44 (January 14, 2009), ¶ 72.

**SR Health and SR Torture:** "The failure to ensure access to controlled medications for pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment." (Letter from Manfred Nowak, Special Rapporteur on Torture, and Anand Grover, Special Rapporteur on the right to the highest attainable standard of health, to Her Excellency Ms. Selma Ashipala-Musavyi, Chairperson of the 52nd Session of the Commission on Narcotic Drugs, December 10, 2008), pg. 4.

**Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment** (1987).

**Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment**, G.A. Res. 37/194, UN Doc. No. A/RES/37/194 (December 18, 1982). Available at <http://www2.ohchr.org/english/law/medicalethics.htm>.

**The European Charter of Patients' Rights**, Art 11: "Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative treatments and simplifying patients' access to them."

**Declaration on the Promotion of Patients' Rights in Europe:** "Patients have the right to relief of their suffering according to the current state of knowledge." [Art. 5.10]. "Patients have the right to humane terminal care and to die in dignity." [Art. 5.11]. WHO, Declaration on the Promotion of Patients' Rights in Europe Arts. 5.10 & 5.11 (Copenhagen: WHO, 1994).

**Council of Europe**, Recommendation 1418, Protection of Human Rights and Dignity of the Terminally Ill and Dying (1999). Available at <http://assembly.coe.int/documents/adoptedtext/ta99/erec1418.htm>.

**Table 2: Palliative care and the right to life**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Unable to obtain pain medication, an AIDS patient is unable to adhere to required treatment and continue taking antiretrovirals. As a result, the patient does not have much time to live.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<b>ICCPR 6(1):</b> Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.	None.

**Other Interpretations**

**HRC General Comment 6:** Explaining that the right to life “should not be interpreted narrowly” or “in a restrictive manner,” and its protection “requires that States adopt positive measures . . . to increase life expectancy.” Paras. 1 and 5 (1982).

**Table 3: Palliative care and the right to the highest attainable standard of health**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>A country does not provide for training in palliative care to its medical personnel. As a result, end-of-life patients do not receive adequate pain relief and physical, psychosocial, and spiritual care.</li> <li>A State provides funding only for hospitals and not for hospices and home-based care facilities. As a result, patients must either forgo treatment or remain far from their homes and families.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<p><b>CESCR General Comment 14:</b> Affirming the importance of “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.” Para. 25 (2000).</p> <p><b>CESCR General Comment 14:</b> Indicating that access to “essential drugs, as defined by the WHO Action Programme on Essential Drugs” is part of the minimum core content of the right to health. Fourteen palliative care medications are currently on the WHO Essential Drug List. Para. 43, (2000).</p> <p><b>CESCR General Comment 14:</b> “States are under the obligation to respect the right to health by . . . refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services.” Para. 34 (2000).</p>
<b>CRC 24(1)</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.	<b>CRC:</b> Noting Belarus’ “adoption of the recent Order on Child Palliative Care” but “recomm[en]d[ing] that the State party establish a funding mechanism for the provision of palliative care for children and support the palliative care services provided by non-governmental organizations” who operate without sufficient financial support. CRC/C/BLR/CO/3-4 (2011), paras. 55,56.

## Table 3(cont.)

### Other Interpretations

**SR Health:** However, many countries have failed to adapt their drug control systems to ensure adequate medication supply; those systems were often enacted before contemporary treatment methods for chronic pain and drug dependence were known or devised. That constitutes an ongoing infringement of the right to health, as the Committee on Economic, Social and Cultural Rights has elaborated that access to essential medicines is a minimum core obligation of the right, and States must comply immediately with this non-derogable obligation regardless of resource constraints. A/65/255 (August 6, 2010).

**SR Health:** “The failure to ensure access to controlled medications for pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment.”

**European Charter of Patients’ Rights**, Art. 11: “Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative treatments and simplifying patients’ access to them.”

**Declaration on the Promotion of Patients’ Rights in Europe**, Art. 5.9: “Patients have the right to enjoy support from family, relatives and friends during the course of care and treatment and to receive spiritual support and guidance at all times.”

**WHO 1978 Declaration of Alma-Ata:** The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.

**G.A. Res. 46/91**, Annex, para. 11, UN Doc. A/RES/46/91 (December 16, 1991): Older persons should have access to health care to help them to gain or regain the optimum level of physical, mental, and emotional well-being and to prevent or delay the onset of illness.

## Table 4: Palliative care and the right to information

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• People are denied information about: hospice and palliative care services; pain management; and their diagnosis and prognosis.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<b>CESCR General Comment 14:</b> Health care accessibility “includes the right to seek, receive and impart information and ideas concerning health issues.” Para. 12(b)(iv), (2000).

### Other Interpretations

**SR Health:** The Special Rapporteur is of the view that a holistic approach to health should also address the process of dying. While this report does not consider issues of patient autonomy in respect of deciding to end life, it is nonetheless necessary to ensure that patients be able to make autonomous, informed decisions regarding the quality of health during the process of dying. That includes choices about access to adequate pain relief and other necessary interventions, location of death, and the ability to refuse treatment designed to prolong life when it is not desired by the patient. This requires clear, candid and non-judgmental discussion with medical practitioners, who should be adequately trained to deal with these delicate issues in order to enable older persons to “die with dignity”, as required from a human rights prospective. A/HRC/18/37 (July 4, 2011).

**The European Charter of Patients’ Rights**, Art. 3: “Every individual has the right of access to all kinds of information regarding their state of health and health services and how to use them, and all that scientific research and technological innovation makes available.”

**The Declaration on the Promotion of Patients’ Rights in Europe**: Art. 2.2: “Patients have the right to be fully informed about their health status, including the medical facts about their conditions; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis, and progress of treatment.”

**European Convention on Human Rights and Biomedicine**, art 10(2): “Everyone has the right to know any information collected about his or her health.” See also Explanatory Report, para. 65-70 (providing interpretation of rights to private life and information contained in Art. 10 (2)).

## Table 5: Palliative care and the right to non-discrimination and equality

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A country decides that it is not worth investing precious resources in providing care for the elderly.</li> <li>• Former drug users are denied access to opioid-based pain medication.</li> <li>• A state provides only limited health services to non-citizens and refugees, denying them access to palliative care.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 2(2)</b> The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status.</p> <p><b>ICESCR 3</b> The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.</p> <p><b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR General Comment 6:</b> “The range of matters” for which discrimination on the basis of age is acceptable “is very limited.” In fact, States parties “are obliged to pay particular attention to promoting and protecting the economic, social and cultural rights of older persons.” Paras. 12 &amp; 13 (1995).</p> <p><b>CESCR General Comment 6:</b> Emphasizing the need “to eliminate any discriminatory legislation and the need to ensure the relevant budget support” for the elderly. Para. 18 (1995).</p> <p><b>CESCR General Comment 6:</b> Upholding “the right of elderly persons to the enjoyment of a satisfactory standard of physical and mental health” and urging of “a comprehensive view, ranging from prevention and rehabilitation to the care of the terminally ill.” Para. 34 (1995).</p> <p><b>CESCR:</b> Recommending that <b>Bulgaria</b> “take affirmative action for the well-being of older people,” in light of their increasing number. [ICESCR, E/2000/22 (1999) 46, para. 238].</p> <p><b>CESCR:</b> Noting “with satisfaction” <b>Finland’s</b> inclusion of age as a prohibited ground of discrimination in its constitution. [CESCR, E/2001/22 (2000) 73, para. 433].</p>

Human Rights Standards	Case Law
<p><b>ECHR 14:</b> The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.</p>	<p><b>ECtHR:</b> The Court considered “the applicant’s complaints that she has been discriminated against in the enjoyment of the rights guaranteed under that provision in that domestic law permits able-bodied persons to commit suicide yet prevents an incapacitated person from receiving assistance in committing suicide.” However, it found no violation of Article 14 because it would be too difficult to judge who is incapable of committing suicide and would undermine the law’s purpose to protect life and to safeguard against abuse. <i>Pretty v. The United Kingdom</i>, no. 2346/02, para 86 (April 29, 2002).</p>

### Other Interpretations

**SR Health:** The right to health clearly proscribes discrimination in respect of age, including within palliative health care services. States are obliged to respect the right to health by refraining from denying or limiting equal access for all persons to palliative health services (E/C.12/2000/4, para. 34). Age-based discrimination that is sanctioned on the basis of risk/benefit profiling cannot under any circumstances be considered appropriate in the context of palliative care, which aims to improve quality of life, rather than its length. A/HRC/18/37 (July 4, 2011).

### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>47</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>48</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>49</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>50</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claim their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

#### **What are key elements of a human rights-based approach?**

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

47 Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

48 For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

49 Ibid.

50 Ibid.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>51</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>51</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.



## 4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF HARM REDUCTION?

This section contains **six examples** of effective human rights-based work in the area of palliative care and human rights. These are:

1. Litigation to Ensure Access to Morphine in India
2. Petitioning the State Human Rights Commission for Access to Palliative Care in India
3. Regulatory Reform in Romania
4. Advocating for Access to Pain Relief through United Nations Mechanisms
5. Integrating Legal Services into Palliative Care
6. Integration of Patients' Rights Standards in Hospice Accreditation in South Africa

## Example I: Litigation to Ensure Access to Morphine in India

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### Project Type

Litigation: Public Litigation Case (No. 942/98) in the Delhi High Court (Dr. R.B. Ghooi).

### The Organization

This is an example of public interest litigation on behalf of cancer patients without access to morphine for palliative care. In 1998, a private citizen, Dr. Ravindra Ghooi, filed a lawsuit on behalf of cancer patients in India. He requested that the court provide rationalization of procedures for the supply of morphine for medical purposes.

### The Problem

In 1985, the Narcotic Drugs and Psychotropic Substances Act (NDPS) enacted strict controls on the manufacture and distribution of morphine in India. This had a tremendous impact on the use of morphine for medical purposes. Supplies of medical morphine plummeted from over 750 kilograms per year in 1985 to only 56 kilograms per year in 1996. Thus, while India was the major exporter of opium to the world, patients with severe pain did not have access to morphine. Moreover, a whole generation of doctors graduated without experience in using morphine for palliative care purposes and unaware of its potential for treating patients.

Dr. Ghooi filed a lawsuit after the death of his mother. His mother had breast cancer, but due to a previous history of diabetes and a stroke, she was not a candidate for aggressive cancer therapy. Nonetheless, she suffered from significant pain. Her physicians were not able to obtain even 1 mg of morphine for her treatment. Dr. Ghooi himself advocated on behalf of his mother, encountering bureaucratic barriers and expending time and money meeting with government officials, but was ultimately unsuccessful.

### Procedure

After exhausting his administrative remedies, Dr. Ravindra Ghooi filed a lawsuit in the Delhi High Court.

### Arguments and Holding

In 1998, the High Court affirmed, “It is a right of patients to receive any medication they need, particularly morphine.” The Court then directed the state government to speedily attend to morphine requests and to pending hospital applications for morphine licenses. It further encouraged patients to approach the court if unsatisfied.

### Commentary and Analysis

#### *Litigation*

This court case worked in tandem with other advocacy efforts to increase access to palliative care medications. In 1999, the Pain and Palliative Care Society formed to develop community-based palliative care provision in India. Over the next seven years, the Society helped to establish twenty outreach palliative care programs throughout Kerala. By 2002, eight of the twenty-eight states in India amended their rules governing access to morphine.

Additionally, Indian physicians, WHO, and academic experts in the US joined together to reform the barriers to pain management. In 1994, Indian physicians formed the Indian Association of Palliative Care (IAPC)—disseminating knowledge of palliative care through regular conferences and a journal. IAPC, the WHO and academic experts in the US worked together with the national Government of India, their counterparts in a number of states, numerous physicians, and their respective pain and palliative organizations throughout India.

#### *International Law*

Nearly every government in the world is a signatory to three international drug control conventions: the Single Convention on Narcotic Drugs of 1961 (the primary treaty regulating opioid compounds and their precursors), the 1971 Convention on Psychotropic Substances (designed to control psychoactive drugs) and the 1988 Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances. These treaties aim to control the illicit use of non-medical uses of opioid drugs, but at the same time recognize the medicinal properties and scientific uses of pain medication. For instance, the Single Convention provides that: “the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes.”<sup>52</sup>

#### *Foreign Law*

Many countries wrote their opioid control laws in a different era. At the time the laws were written, countries understood addiction to be characterized by withdrawal symptoms upon cessation of use. Since opioids always produced withdrawal symptoms upon cessation, lawmakers across the world believed that opioid use inevitably led to dependence. We now understand addiction as defined by compulsive behavior and continued use despite harm or drug-related problems, whether or not physical dependence is present. Therefore, the laws of many countries reflect an outdated understanding of addiction.

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<sup>52</sup> United Nations, Single Convention on Narcotic Drugs, 1961, as amended by the 1972 Protocol mending the Single Convention on Narcotic Drugs, 1961, Preamble, p. 1; Accord United Nations, Convention on Psychotropic Substances, 1971, Preamble, p. 1.

## Example 2: Petitioning the State Human Rights Commission for Access to Palliative Care in India

### Project Type

Advocacy

### The Organization

Located in Kerala, India, the Institute of Palliative Medicine, Calicut (IPM), is the first World Health Organization Collaborating Center (WHOCC) in the developing world and the fifth WHOCC in Palliative Care in the world overall. The IPM is the leading training institution for palliative care in Asia.

### The Problem

In India, medical professionals do not receive training in palliative care as part of their medical education. Also, India has no palliative care policy and most states continue to implement strict drug control laws even on medicines with palliative care purposes. Terminally ill patients in Kerala could not obtain needed palliative care from trained professionals or pain relief medication.

### Human Rights Commission Decision

[www.kshrc.kerala.gov.in/archives.htm](http://www.kshrc.kerala.gov.in/archives.htm)

### Report

Economist Intelligence Unit, Ranking end-of-life care around the world (highlighting Kerala's program on pg 24-25). [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

### Actions Taken

A cancer patient and the Director of the Institute of Palliative Medicine petitioned the State Human Rights Commission for the provision of palliative care in government hospitals in the State of Kerala.

### Results and Lessons Learned

The Human Rights Commission issued its recommendations in 2006, giving the Government 30 days to produce an action-taken report. The recommendations declared palliative care as part of the right to life guaranteed under Article 21 of the Constitution. To this end, the Human Rights Commission directed the government to make palliative care a compulsory part of medical education and practice by, among other things:

- taking steps to include palliative medicine in the curriculum of nursing and undergraduate medical students;
- providing training in palliative care to medical staff in government and private hospitals;
- setting up a pain and palliative care hospital in every district; and
- providing enough medicines for relieving pain.

The recommendations also include substantive guidelines for palliative care training, stating that training should inform medical professionals on (i) communication, (ii) legal decision making, (iii) pain in cancer patients, (iv) medical complications in patients with terminal illness, (v) psychiatric and neuro problems of patients with terminal illness, and (vi) spiritual support to terminal patients with terminal illness.

The Government took several steps to develop the palliative care program in Kerala. First, it adopted a Palliative Care Policy (2008). The policy outlines the Government's commitment to palliative care, proposed a new law to ensure availability of palliative care medicines, and established the guidelines on palliative care education for health care professionals.

“The detection of cancer in a parent is a calamity for the children, spouse and affected parent. During the last days of our mother’s life, we alternately watched her for signs of pain, keeping an eye on the amount of (weaker) painkillers in hand. We spent a fortune in time and money on meeting Government officials—we knocked on the door of every Government official concerned with narcotic control. We were surprised to find that the officials were sympathetic to our case; clerks and officers who are labeled as bureaucratic, were courteous and kind. We received tons of sympathy, but not a milligram of morphine.”

–Ghooi RB. “A mother in pain”. *The Lancet* 1998; 352;1625.

Second, the Government amended the Kerala Narcotic Drugs and Psychotropic Substances Rules (1985) in 2009. This modified the laws on procuring and dispensing morphine, and simplified the process of licensing for health care centers. With the amendment of this law, morphine became more available and shortages were no longer a problem. The Government also issued a brochure on the Standard Operating Procedures (SOP) involved in applying for licensing, and how to procure and dispense morphine (available at [www.instituteofpalliativemedicine.org/sop.pdf](http://www.instituteofpalliativemedicine.org/sop.pdf)).

The palliative care program in Kerala has become a model for palliative care initiatives in developing countries. Today, there are more than 200 community based organizations that provide palliative care services and more than 300 government initiatives. In addition to strong high-level policy guidance, a community level organization called the Neighbourhood Network in Palliative Care (NNPC) was created in 2001. NNPC is instrumental to the palliative care success in Kerala through its provision of thousands of palliative care volunteers, who are supported by medical professionals.

**Pain and Palliative Care Society**

*Medical College, Calicut, Kerala, India*

Web: [www.painandpalliativecare.org](http://www.painandpalliativecare.org)

**Institute of Palliative Medicine Calicut**

*Medical College, Calicut, Kerala, India*

Web: [www.instituteofpalliativemedicine.org](http://www.instituteofpalliativemedicine.org)

## Example 3: Regulatory Reform in Romania

### Project Type

Regulatory Reform

### The Organization

A team of health care workers in Romania worked with the Pain & Policy Studies Group at the University of Wisconsin to convince Romania's regulators that a change in that country's opioid control policy was necessary.

### The Problem

Romania's drug-control policies were more than 35 years old and imposed an antiquated regulatory system on pain medication based on inpatient, post-surgical management of acute pain. This restricted prescription authority of opioids to only in-hospital patients who had just undergone surgery, making access to opioid treatment difficult for patients with severe chronic pain due to cancer or AIDS.

### Actions Taken

In 2002, a Romanian team composed of health care professionals, representatives from narcotic authorities and the ministries of health, social welfare, and insurance industry -- all working on cancer, HIV/AIDS, pain, and palliative care issues -- attended an International Palliative Care Initiative (IPCI) workshop on ensuring the availability of opioid analgesics for palliative care.

The Romanian team returned home and advocated for the creation of a national commission to reform Romania's opioid control policies. To convince regulators that a change in opioid law was needed, the team cited to Romania's patient rights law, which stated, "The patient has the right to palliative care in order to die in dignity." (24/2003, Cap VI, art. 31). The Ministry of Health agreed to form a Palliative Care Commission (PCC) to study the matter. Finding that Romania's opioid control policies fell short of WHO guidelines, the PCC invited the Pain & Policy Studies Group from the University of Wisconsin to collaborate in the preparation of recommendations.

### Results and Lessons Learned

#### *Altered legislation and regulation*

Based on the resulting report, the Ministry of Health drafted legislation to replace the old narcotics law. Parliament passed this into law in 2005.<sup>53</sup> The Pain and Policy Studies Group then worked with the Ministry of Health on implementing regulations. In 2006, the Ministry of Health approved the regulations.<sup>54</sup>

### Additional Resource

WHO, Achieving Balance in National Opioids Control Policy: Guidelines for Assessment (2000). [www.medsch.wisc.edu/painpolicy/publicat/oowhoabi/oowhoabi.htm](http://www.medsch.wisc.edu/painpolicy/publicat/oowhoabi/oowhoabi.htm)

- This document served as a basis for the legislation. It outlines the need to balance modern pain management with obligation to control non-medicinal or recreational use of opioids.

<sup>53</sup> Law no. 339/29.11.2005 on the legal status of narcotic and psychotropic plants, substances and preparations. Official Journal no. 1095, December 5, 2005.

<sup>54</sup> Government decision nr. 1916/2006 regarding approval of regulations of law 339/2005. Monitorul Oficial (Official Journal) 18/11.01.2007.

*Greater authority to prescribe opioid medication*

The new law grants greater authority to professionals to prescribe opioids and fewer restrictions on dosages and disease requirements. Special authorization is no longer necessary to prescribe opioid medications for outpatients (patients not admitted to a hospital). As well, non-specialists can prescribe opioids after receiving certified training. The law eliminated both dosage limitations and restrictions to approved diseases,<sup>55</sup> freeing health care professionals to prescribe opioids for any condition and in any dosage. Every doctor has the authority to prescribe strong opioid medications, according to his/her medical judgment.

*Educating doctors*

With this radically expanded authority to prescribe opioid medications, it was important for doctors to receive education on pain management. Article 54 of the regulations provided that: “Universities of medicine and pharmacy, the Ministry of Public Health, the College of Physicians from Romania, the College of Pharmacists from Romania and professional or scientific societies, as well as other suppliers of professional training shall take measures for the regular organization of training, courses for adequate therapy of pain and prescribing, use and legal status of narcotic and psychotropic plants, substances and preparations.” Romania is currently conducting a country-wide effort to educate health care professionals in the use of opioid analgesics. With a 15-month grant from the Open Society Institute, Hospice Casa Sperantei took the lead in training physicians in palliative care. The curriculum includes 20 hours of classroom teaching on two consecutive weekends, and six hours of clinical practice in each physician’s practice setting. After completing the course, physicians receive a certificate from the Ministry of Health.

**Results**

The new law and regulations were a result of a four-year project between local professionals, international experts and national authorities. The new legislation and regulations meet the WHO guidelines and increase access to palliative care medicines.

**Hospice Care Sperantei**

Brasov, Romania

Email: [hospice@hospice.ro](mailto:hospice@hospice.ro)

Website: <http://www.hospice.ro>

Website English: <http://www.hospice.ro/en/>

**University of Wisconsin, Pain and Policies Study Group**

Madison, Wisconsin, USA

Website: [www.painpolicy.wisc.edu](http://www.painpolicy.wisc.edu)

<sup>55</sup> Under the old law, doctors could only prescribe opioids to patients suffering from advanced cancer or with obliterative arteritis with necrosis. Law no. 73/29.12.1969 on the legal status of narcotic substances and preparations. Official Journal 154/29.12.1969). Dec. 1969.



## Example 4: Integration of Patients' Rights Standards in Hospice Accreditation in South Africa

### Project Type

Standard-setting

### The Organizations

Hospice and Palliative Care Association of South Africa (HPCA). Founded in 1988, the HPCA is a professional membership organization for hospice and palliative care organizations. It operates in all nine provinces of South Africa and has 189 member and affiliated hospitals. One of its core missions is to ensure professional palliative care services and to guarantee a high standard of care for patients and their families. Patient rights are central to HPCA's philosophy—providers view themselves as advocates for their patients—and would thus have to figure prominently in criteria developed.

The Council for Health Service Accreditation of Southern Africa (COHSASA). COHSASA grew out of the Faculty of Medicine at the University of Stellenbosch's Pilot Accreditation Programme for South African Health Services. In 1996, COHSASA began operating as an independent, non-partisan unit. It has since developed health accreditation programs for hospitals, sub-acute care, psychiatric facilities and programs, and primary health care clinics. Their mission is to “assist healthcare facilities in developing countries to deliver quality healthcare to their clients through sustained improvement, using internationally recognised standards and based on patient safety principles and operational research.”

### The Problem

Patients with HIV/AIDS, cancer, chronic disease, terminal illness, other patients, and the elderly often suffer moderate to severe pain, and palliative care helps to relieve their pain and suffering. South Africa, for example, has approximately 5.6 million people living with HIV/AIDS and approximately 69,000 people with cancer. It is therefore necessary to develop a standard of care and an accreditation program for palliative care programs across the country to encourage hospital and hospices to meet and maintain minimum quality standards—a strategy that could improve patient safety and better the overall quality of care.

### Example from South Africa:

#### Legal Aspects of Palliative Care Manual (2nd Edition, 2012)

This manual addresses the legal and human rights problems facing people with life-threatening illness. It now not only includes case studies, legal recommendations, and resources, but has been restructured as a training manual with step-by-step lessons for hospice and palliative care staff and legal practitioners.

[www.hpca.co.za/Legal\\_Resources.html](http://www.hpca.co.za/Legal_Resources.html)

### Actions Taken

- HPCA developed palliative care standards for the accreditation of hospices in South Africa, incorporating key protections for patient rights.
- In 1994, a HPCA Standards Committee was created to work with the COHSASA, the accrediting body for facilities in compliance with health professional standards, to formulate comprehensive palliative care standards for hospices.

- The Committee developed standards covering 13 key areas with patient rights as one of them. Patient rights language is further embedded throughout.
- A chapter on patient rights addresses processes to: identify, protect and promote patient rights; inform patients of their rights; include the patient and the patient's family, when appropriate, in decisions about the patient's care; obtain informed consent; educate staff about patients' rights; and guide the organization's ethical framework.

### Results and Lessons Learned

In 2005, the HPCA/Cohsasa standards for hospice accreditation were published and recognized by the International Society for Quality in Health Care Incorporated (ISQua). 26 hospices are currently fully accredited in 2012.

#### **Hospice Palliative Care Association of South Africa (HPCA)**

Cape Town, South Africa

Email: [info@hpca.co.za](mailto:info@hpca.co.za)

Website: [www.hospicepalliativecaresa.co.za/](http://www.hospicepalliativecaresa.co.za/)

#### **COHSASA (Council for Health Services Accreditation of Southern Africa)**

Cape Town, South Africa

Email: [queries@cohsasa.co.za](mailto:queries@cohsasa.co.za)

Web: [www.cohsasa.co.za](http://www.cohsasa.co.za)

## Example 5: Integrating Legal Services into Palliative Care

### Project Type

Legal Services

### The Organization

Founded in 2005, the Kenya Hospices & Palliative Care Association (KHPCA) is a national advocacy organization that works to represent palliative care providers in Kenya. The mission of KHPCA is to make palliative care available to those who are in need by making palliative care in Kenya more affordable, accessible and of higher quality.

### The Problem

The provision of legal services can play a critical role in improving the quality of life for patients and families dealing with life-threatening illnesses. Legal services can address human rights violations that negatively affect a patient's health and contribute to his/her and families' peace of mind and well-being by providing answers to urgent and often difficult questions. Integrated health and legal services allow for both holistic care and increased access to justice, taking the law out of the courtroom and private offices and into the community. Common legal needs include: "[a]ccess to health services and other social benefits, empowerment to make medical decisions, writing wills, planning for children and other dependents, [and] protecting/disposing of property."<sup>56</sup> Approximately 1.5 million Kenyans live with HIV/AIDS, and approximately 45,000 Kenyans live with some form of cancer. Since many patients with HIV/AIDS and cancer suffer from moderate to severe pain, there is a clear need to provide quality palliative care in Kenya.

### Kenya Hospices & Palliative Care Association (KHPCA)

- Region: Eastern and Southern Africa
- Field of work: treatment, care and support; training of palliative care staff in hospitals; and legal assistance.
- Populations served: people living with HIV; patients with cancer, non-communicable diseases; TB patients; and children with life-limiting illnesses.
- Staff: 7 full-time, 1+ volunteers.

### Actions Taken

KHPCA recently surveyed three hospices in Kenya to assess the medical and legal rights involved in palliative care. The study focused on patients, medical practitioners, legal practitioners, volunteers and caregivers. After learning the results of the survey, KHPCA developed and administered a project to create a more holistic approach to health care—providing health and legal services for patients in need.

### Results and Lessons Learned

The survey revealed that there is limited access to palliative care; inadequate information regarding patient suffering; a general lack of awareness on patients' rights; discrimination against those with life-threatening illnesses; and a need to review laws and policies to incorporate palliative care into the public health system of Kenya.<sup>57</sup> From the study, KHPCA concluded that:

<sup>56</sup> David Musyoki, Kenya Hospices and Palliative Care Association, 3rd Kenya National Palliative Care Conference 2012 65 (Sept. 12-14 2012). Available at: [http://kehpc.org/conference/wp-content/uploads/2012/09/conference\\_final\\_programme.pdf](http://kehpc.org/conference/wp-content/uploads/2012/09/conference_final_programme.pdf)

<sup>57</sup> David Musyoki, Kenya Hospices and Palliative Care Association, Incorporation of Legal and Human Right Issues in Palliative Care. Available at: <http://kehpc.org/wp-content/uploads/AT39.pdf>

*There is need to train all those involved in the care of these patients on the palliative care approaches. In such settings, there is need to have standard protocol in dealing with such patients, striking a critical balance between the ethical-legal concerns with humane approach to care. Early diagnosis & referral, the presence of family will help in modifying the disease trajectory, hence improving patients' quality of life.<sup>58</sup>*

To address these gaps between legal rights and the provision of palliative care in Kenya, KHPCA has worked with several hospices to empower hospice workers, patients and their families on their palliative care rights. Additionally, KHPCA is now a key partner with the Kenyan Government in enhancing pain relief and palliative care throughout Kenya. Specifically, KHPCA works with the Kenyan Government to develop and implement national palliative care guidelines; develop curricular and training materials for palliative care; train health care providers and care givers on palliative care; conduct awareness campaigns on palliative care targeting policy makers public, media, health care personnel and regulators; advocate for legislation and policies that support palliative care; and integrate palliative care services into the national health services.<sup>59</sup>

#### **Kenya Hospices & Palliative Care Association (KEHPCA)**

Nairobi, Kenya

Email: [info@kehpc.org](mailto:info@kehpc.org)

Website: [www.kehpc.org](http://www.kehpc.org)

## **Additional Resources**

National Cancer Control Strategy: Republic of Kenya, Ministry of Public Health and Sanitation and Ministry of Medical Services, National Cancer Control Strategy 2011-2016. <http://kehpc.org/wp-content/uploads/Kenya-National-Cancer-Control-strategy.pdf>.

### **KHPCA Resources on Palliative Care:**

Kenya Hospices and Palliative Care Asso. [http://kehpc.org/wp-content/uploads/kehpc\\_brochure.pdf](http://kehpc.org/wp-content/uploads/kehpc_brochure.pdf)

Patient Information Sheet.: [http://kehpc.org/wp-content/uploads/pain\\_brochure.pdf](http://kehpc.org/wp-content/uploads/pain_brochure.pdf)

Palliative Care Patients' Rights. [http://kehpc.org/wp-content/uploads/pc\\_rights.pdf](http://kehpc.org/wp-content/uploads/pc_rights.pdf)

What is Power of Attorney. <http://kehpc.org/wp-content/uploads/attorney.pdf>

Guidelines to Making a Will. <http://kehpc.org/wp-content/uploads/a%2owill.pdf>

### **Conference Report**

African Palliative Care Association, Palliative Care: An Essential Part of Medical and Nursing Training (March 24-25, 2011, Nairobi, Kenya). <http://kehpc.org/wp-content/uploads/education%2oconference.pdf>

<sup>58</sup> David Musyoki, Kenya Hospices and Palliative Care Association, 3rd Kenya National Palliative Care Conference 2012 65 (Sept. 12-14 2012). Available at: [http://kehpc.org/conference/wp-content/uploads/2012/09/conference\\_final\\_programme.pdf](http://kehpc.org/conference/wp-content/uploads/2012/09/conference_final_programme.pdf)

<sup>59</sup> Republic of Kenya, Ministry of Public Health and Sanitation and Ministry of Medical Services, National Cancer Control Strategy 2011-2016 30. Available at: <http://kehpc.org/wp-content/uploads/Kenya-National-Cancer-Control-strategy.pdf>

## Example 6: Advocating for Access to Pain Relief Through United Nations Mechanisms

### Project Type

Advocacy

### The Organization

Founded over 30 years ago, Human Rights Watch (HRW) is a leading independent organization that protects and defends human rights across the globe. They conduct objective and rigorous investigations and engage in vigorous advocacy efforts.

### The Problem

Governments have the positive obligation to protect their people from unnecessary pain related to a health condition. Additionally, governments have a negative obligation not to arbitrarily interfere with the provision of essential health services.

Millions require controlled medications, like morphine, for treatment of moderate to severe pain. However, in over 150 countries across the world, access to palliative care medication is virtually non-existent. These medicines are unavailable or inaccessible in many countries because of overregulation and/or problems with supply and distribution systems for controlled medicines. Governments that report low consumption of morphine to the International Narcotics Control Board relative to the number of its citizens suffering from HIV/AIDS or cancer indicates a substantial gap between those suffering and in need of pain management and the actual accessibility of palliative care medicines

## Human Rights Watch

*Health and Human Rights Division*

As part of Human Rights Watch's long commitment to defending human rights, the organization has been reporting on issues related to health and human rights for many years. Human Rights Watch's work has examined how such rights as freedom of speech, expression, assembly and information; freedom from discrimination and arbitrary detention; property rights; bodily autonomy, protection from violence, cruel, inhuman and degrading treatment and torture; and the right to health care intersect with the realization of the right to health. Investigations and advocacy have particularly focused upon the health of vulnerable populations, including women, children, prisoners, displaced persons, lesbian, gay, bisexual, transgender (LGBT) persons, drug users, ethnic and racial minorities, and migrant workers.

[www.hrw.org/sites/default/files/related\\_material/HRW\\_healthbrochure\\_low.pdf](http://www.hrw.org/sites/default/files/related_material/HRW_healthbrochure_low.pdf).

### Actions Taken

Human Rights Watch advocates for palliative care as a human right, including increased access to medications to manage and relieve pain. Its advocacy efforts include country reports and outreach to UN human rights bodies, including the Commission on Narcotic Drugs and the World Health Assembly. Actions taken include:

1. Country reports documenting gaps in policy and practice relating to palliative care in Thailand, Russia, Ukraine, the United States, Canada, Kenya, China, Bangladesh, India, and Kazakhstan, among other countries. Reports available at: <http://www.hrw.org/en/news/2009/03/09/un-drug-summit-undo-decade-neglect#pain>.

- Submission to the Human Rights Committee and the Committee Against Torture regarding Cameroon's Fourth Periodic Report (26 August 2009). Report available at: <http://www.hrw.org/es/news/2009/08/26/submission-human-rights-committee-regarding-cameroon-s-fourth-periodic-report>; [www.hrw.org/en/news/2009/08/26/submission-committee-against-torture-regarding-cameroon-s-fourth-periodic-report](http://www.hrw.org/en/news/2009/08/26/submission-committee-against-torture-regarding-cameroon-s-fourth-periodic-report).

Both reports advocate for the government of Cameroon to effectuate low-cost reforms to remove barriers and ensure adequate supply of opioid medications to treat tens of thousands of Cameroonians experiencing pain and suffering moderate to severe pain associated with cancer, AIDS, and other health conditions.

- Joint Statement of the International Harm Reduction Association and Human Rights Watch, Interactive Dialogue with the Special Rapporteur on Torture at the Tenth Session of the Human Rights Council (12 March 2009). [www.hrw.org/en/news/2009/03/12/joint-statement-international-harm-reduction-association-ihra-and-human-rights-watch](http://www.hrw.org/en/news/2009/03/12/joint-statement-international-harm-reduction-association-ihra-and-human-rights-watch).

The Human Rights Council was urged to reject restrictive drug policies which perpetuate the denial of access to essential medicines, to reject such approaches by the UN Committee on Narcotic Drugs (CND), and to mainstream human rights into international drug policy.

- 'Please, Don't Make Us Suffer Anymore...': Access to Pain Treatment as a Human Right (2009). [www.hrw.org/en/news/2009/03/02/un-stop-needless-suffering](http://www.hrw.org/en/news/2009/03/02/un-stop-needless-suffering).

HRW calls on the UN General Assembly to consider access to pain relief medication. It highlights the causes of poor availability, including "failure to put in place functioning supply and distribution systems; absence of government policies to ensure their availability; insufficient instruction for healthcare workers; excessively strict drug-control regulations; and fear of legal sanctions among healthcare workers."

- Global State of Pain Treatment: Access to Medicines and Palliative Care (2011). Available at: <http://www.hrw.org/sites/default/files/reports/hhro511W.pdf>.

HRW uses publicly available data on the consumption of pain medicines to illustrate the unmet need for pain treatment. It also presents the results of a survey of healthcare workers in 40 countries regarding the main barriers to better pain treatment and palliative care.

- Report of the Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, A/HRC/22/53 (February 1, 2013). Available at: [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

The Special Rapporteur cites to evidence collected by Human Rights Watch of human rights abuses in health care settings, including denial of morphine and other drugs for pain management.

### Results and Lessons Learned

HRW's continued advocacy has brought attention the issues of the international narcotics conventions and access to essential medicines for palliative care. Their reports highlight the issue areas and document human rights violations.

**Human Rights Watch**  
New York, USA  
Website: [www.hrw.org](http://www.hrw.org)

## 5. WHERE CAN I FIND ADDITIONAL RESOURCES ON PALLIATIVE CARE AND HUMAN RIGHTS?

A list of commonly used resources on palliative care and human rights follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Statements and Declarations
- D. Palliative Care as a Human Rights
- E. Palliative Care – General Resources
- F. Essential Medicines and Human Rights
- G. Litigation and Legal Services
- H. Key Populations – Cancer Patients
- I. Key Populations – Children
- J. Key Populations – Older Persons
- K. Key Populations – End-of-Life Care
- L. Key Populations – HIV and Aids Patients
- M. Key Populations – People who use drugs
- N. Key Populations – TB Patients
- O. Multimedia
- P. Advocacy and Training Manuals
- Q. Websites

### A. International Instruments

#### **Binding**

- UN Office on Drugs and Crime, Single Convention on Narcotic Drugs (1961; amended 1972). [www.unodc.org/unodc/en/treaties/single-convention.html](http://www.unodc.org/unodc/en/treaties/single-convention.html).

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- UN General Assembly, *Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS*, A/RES/65/277 (July 8, 2011). [www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610\\_un\\_a-res-65-277\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_un_a-res-65-277_en.pdf).
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## 6. WHAT ARE THE KEY TERMS RELATED TO HUMAN RIGHTS IN PALLIATIVE CARE?

### A

#### Acute pain

Pain that has a known cause and occurs for a limited time. It usually responds to analgesic medications and treatment of the cause of the pain.

#### Addiction

A commonly used term describing a pattern of drug use that indicates physical or mental dependence. It is not a diagnostic term and is no longer used by the World Health Organization (WHO).

#### Advance medical directives

Used to give other people, including health care providers, information about a patient's own wishes for medical care. Advance directives are important in the event patients are not physically or mentally able to speak for themselves and make their wishes known. The most common types of advance directives are the living will and the durable power of attorney for health care. A Do Not Resuscitate (DNR) is also a form of an Advance Medical Directive.

#### Analgesic medications

Medications used to prevent or treat pain.

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### B

#### Bereavement

The act of grieving the loss of a significant other.

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### C

#### Cancer

An abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize (spread).

#### Caregiver

Any person who provides care for the physical, emotional, or spiritual needs of a family member or friend.

#### Chronic pain

Pain that occurs for more than one month after an injury has healed, that occurs repeatedly over months, or is due to a lesion that is not expected to heal.

#### Complementary therapies

Approaches to treatment that are outside of mainstream medical practices. Complementary therapy treatments used for pain and/or comfort include: acupuncture, low-level laser therapy, meditation, aroma therapy, Chinese medicine, dance therapy, music therapy, massage, herbal medicine, therapeutic touch, yoga, osteopathy, chiropractic treatments, naturopathy, and homeopathy.

#### Community based care

Medical and social service care often provided by volunteer trained members of the community.

**D****Death**

The end of life in a biological organism, marked by the full cessation of its vital functions.

**Do Not Resuscitate (DNR) orders**

A DNR is a medical directive that gives consent from the patient, his/her advocate or from a medical physician that the patient is not to be treated for cardiac or respiratory arrest. This directive is used when treatment of the patient will not be beneficial or successful to the quality or longevity of the patient's life. This is usually the case in the seriously and terminally ill, and/or the frail and elderly. These directives do not mean that comfort measures will be withheld.

**Dignity**

The quality of being worthy, honored, or esteemed. Human rights are based on inherent human dignity and aim to protect and promote it.

**Durable power of attorney**

A person who is dying may appoint someone else to manage their finances and to make economic decisions on their behalf. This person is referred to as the "agent."

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**E****End-of-life care**

Doctors and caregivers provide care to patients approaching the end of life that is focused on comfort, support for the family, and treatment of psychological and spiritual concerns.

**Essential medicines**

Medicines that satisfy the priority health care needs of the population. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.

**Ethics**

A system of moral principles and rules that are used as standards for professional conduct. Many hospitals and other health care facilities have ethics committees that can help doctors, other healthcare providers, patients, and family members in making difficult decisions regarding medical care. This may vary with religious and cultural backgrounds.

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**G****Grief**

The normal process of reacting to a loss. The loss may be physical (such as a death), social (such as divorce), or occupational (such as a job). Emotional reactions of grief can include anger, guilt, anxiety, sadness, and despair. Physical reactions of grief can include sleeping problems, changes in appetite, physical problems, or illness.

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**H****HAART**

Highly active anti-retroviral therapy.

**Health care proxy**

A written instrument in which an individual legally delegates authority to another person to make certain health-related decisions on their behalf.

**Home based care**

Medical and social care provided by trained health care professionals or volunteers in a person's home.

**Hospice**

A care program that provides a centralized program of palliative and supportive services to dying persons and their families, in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in specialized inpatient settings.

**Hospice care**

Care designed to give support to people in the final phase of a terminal illness, and focused on comfort and quality of life, rather than a cure. The goal is to enable patients to be comfortable and free of pain so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home -- in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to treat the whole person by providing support for the patient's emotional, social, and spiritual needs, as well as addressing medical symptoms.

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**I****Informed consent**

The process of making decisions about medical care that is based on factual, open, and honest communication between the health care provider and the patient and/or the patient's family members.

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**L****Life-limiting illness**

An illness with a prognosis of a year or less to live.

**Life-threatening illness**

An illness serious enough that a patient may die.

**Living will**

A legal document which outlines the direction of medical care a patient wishes to have or not to have. The living will is used only if the patient becomes unable to make decisions for him/herself, and will be carried out as the patient has directed in the document.

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**M****Medical power of attorney**

A document that allows any individual to appoint another person to be their agent and make decisions for them should they become unable to make decisions for themselves.

**Multidisciplinary team**

A group of individuals representing different medical disciplines who work together to care for a patient and family.

**N****Nursing home**

A residential facility for persons with chronic illness or disability, particularly older people who have mobility and eating problems. This is also called a convalescent home or long-term care facility.

**Nutrition Hydration**

Intravenous (IV) fluid and nutritional supplements given to patients who are unable to eat or drink by mouth, or those who are dehydrated or malnourished.

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**O****Opioid**

A type of medication related to opium. Opioids are analgesics used in acute and chronic pain. Opioids include morphine, codeine, and a large number of synthetic (man-made) drugs like methadone and fentanyl.

**Opportunistic infections**

Infections caused by organisms that usually do not cause disease in a person with a healthy immune system, but can affect people with a poorly functioning or suppressed immune system.

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**P****Pain**

An unpleasant feeling that may or may not be related to an injury, illness, or other bodily trauma. Pain is complex and differs from person to person, as related to the individual's pain threshold.

**Palliative care**

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

**Palliative care for children**

Represents a special, albeit closely related field to adult palliative care for children with life threatening or chronic disorders and their families. Includes active total care of the child's body, mind, and spirit; family support; and a multidisciplinary approach that includes the family and makes use of available community resources.

**Palliative care standards**

Standards reflecting the level of care a patient and family can expect to receive when dealing with a diagnosis of a life-limiting illness.

**Permanent guardianship of minor children**

Offers a parent the option of permanently placing their child (a minor) in the care of another person.

**Power of attorney for personal care**

A legal document that specifies one or more individuals a patient would like to make medical decisions on his/her behalf if unable to do so on their own.

**Psychology**

Science dealing with phenomena of the mind, the conscious subject, or self.

**Psychosocial care**

Care given to meet a constellation of social, mental health, and emotional needs.

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**R****Rehabilitation**

Treatment for an injury, illness, or pain with the goal of restoring partial or full function.

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**S****Social work**

Work carried out by professionals concerned with social problems, their causes, their solutions, and their human impacts. Social workers work with individuals, families, groups, organizations, and communities, as members of a profession committed to social justice and human rights.

**Spiritual care**

Providing the necessary resources to address and support people's values and beliefs, provided these values and beliefs place no individuals at risk. It is based on treating each person with respect and dignity, promoting love, hope, faith, and helping vulnerable people to find the strength to cope at times of life crises when overcome by despair, grief, and confusion.

**Suffering**

Absence of any power to control or to meaningfully influence a perceived process of one's own disintegration.

**Symptom management**

Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of symptom management is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called palliative care, comfort care, and supportive care.

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**T****Terminal**

A progressive disease that is expected to cause death.

**Treatment withholding**

When treatment is considered to be ineffective, disproportionate, or of no value to the patient's quality of life, it may be withdrawn or withheld.

**Treatment withdrawal**

The ending of treatment that is medically futile in promoting an eventual cure or possible control of the disease.



**W****Will**

A legal document that allows a person to leave any portion of his/her estate and any specific positions to any other person or organization.

**Withholding care**

Not offering a specific treatment to a patient.

**Withdrawing care**

Withdrawing a treatment that has already started in a patient.

# CHAPTER 6



## CHILDREN'S HEALTH AND HUMAN RIGHTS

“ By giving high priority to the rights of children, to their survival and to their protection and development, we serve the best interest of all humanity. ”

— *A World Fit for Children*

**Health and Human Rights Resource Guide**

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Cover photograph courtesy of Angela Duger, “Family in Northern Lao PDR”

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# INTRODUCTION

This chapter will introduce you to key issues and resources in children's health and human rights. Several issues herein are touched upon in other chapters. For more information on children, adolescents, and HIV, please see Chapter 2 on HIV, AIDS and Human Rights. For more information on children, adolescents, and indigenous and minority health please see Chapter 7 on Minority Health and Human rights. This chapter is organized into six sections that answer the following questions.

1. How is children's health a human rights issue?
2. What are the most relevant international and regional human rights standards related to children's health?
3. What is a human rights-based approach to advocacy, litigation and programming?
4. What are some examples of effective human rights-based work in the area of children's health?
5. How can I find additional resources about the health and human rights of children?
6. What are key terms related to children's health rights?

# I. HOW IS CHILDREN'S HEALTH A HUMAN RIGHTS ISSUE?

## What are children's health rights?

Under international human rights law, children are entitled “to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.” This right is articulated in Article 24 of the 1989 UN Convention on the Rights of the Child (CRC), which is the most widely ratified international human rights instrument<sup>1</sup> and consolidates all previous treaties on the rights of children.<sup>2</sup> The right to health for children has long been understood as an “inclusive” right, which extends beyond protection from immediately identifiable infringements such as limitations on access to health care or services, and includes the wide range of rights and freedoms that are determinate to children's health, such the rights to non-discrimination, access to health-related education and information, and freedom from harmful traditional practices.<sup>3</sup> The realization of a child's right to health also requires access to underlying conditions for health, such as “safe water and adequate sanitation, adequate nutritious food and housing, [and] healthy occupational and environmental conditions.”<sup>4</sup>

The CRC and its Optional Protocols articulate the rights of children (from the perspective of the child “rights-holder”) as well as the responsibilities of State Parties (“duty-bearer”). The CRC is legally binding on all signatories, and also establishes a framework for protection of health rights that are not explicitly provided for in the Convention, for example, the rights of children affected by HIV.<sup>5</sup> The CRC defines a child as “every human being below the age of eighteen years.”<sup>6</sup> Such a definition includes adolescence, commonly understood to be between the ages of 10 and 19 years.<sup>7</sup> Consequently, the CRC imposes on State Parties a legally binding obligation to give effect to the child-specific health rights of *all* children, including adolescents, up to 18 years of age.<sup>8</sup>

- 1 To date, 193 State Parties have ratified the CRC. The United States of America and Somalia have signed but not ratified the Convention; for the status of signatures, ratifications, and accessions, see: United Nations General Assembly (UNGA), *Convention of Rights of the Child* (1989). [http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-11&chapter=4&lang=en](http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-11&chapter=4&lang=en).
- 2 UN General Assembly, *Geneva Declaration on the Rights of the Child*, G.A. Res. 1386 (XIV), 14 U.N. GAOR Supp. (No. 16) at 19 UN Doc. 1/4354. U.N. GAOR Supp. (No. 16) at 19, U.N. Doc. A/4354, art. 4. [www.unicef.org/lac/spbarbados/Legal/global/General/declaration\\_child1959.pdf](http://www.unicef.org/lac/spbarbados/Legal/global/General/declaration_child1959.pdf).
- 3 UN Office of the High Commissioner of Human Rights (OHCHR) and World Health Organization (WHO), *The Right to Health*, Fact Sheet No. 31. [www.ohchr.org/Documents/Publications/Factsheet31.pdf](http://www.ohchr.org/Documents/Publications/Factsheet31.pdf).
- 4 UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14*, para. 45, in Nolan A, Yamin AE and Meier BM, *Submission on the Content of a Future General Comment on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art. 24)* (OHCHR). [http://www2.ohchr.org/english/bodies/crc/calls/submissions/CRC\\_received.htm](http://www2.ohchr.org/english/bodies/crc/calls/submissions/CRC_received.htm).
- 5 UN Office of the High Commissioner of Human Rights, “Committee on the Rights of the Child – General Comments.” <http://www2.ohchr.org/english/bodies/crc/comments.htm>.
- 6 A particular country's laws may define majority at an earlier age. To date, 193 State Parties have ratified the CRC. The United States of America and Somalia have signed but not ratified the Convention. UN General Assembly, *Convention on the Rights of the Child (CRC)*, G.A. Res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989); 28 I.L.M. 1448 (1989). [www.ohchr.org/english/law/crc.htm](http://www.ohchr.org/english/law/crc.htm).
- 7 World Health Organization, *The second decade: improving adolescent health and development* (2001). [www.who.int/maternal\\_child\\_adolescent/documents/frh\\_adh\\_98\\_18/en/index.html](http://www.who.int/maternal_child_adolescent/documents/frh_adh_98_18/en/index.html).
- 8 UN Committee on the Rights of the Child (CRC Committee), *General Comment No. 4: Adolescent health and development in the context of the Convention on the Rights of the Child*, CRC/GC/2003/4 (2004). <http://tb.ohchr.org/default.aspx?Symbol=CRC/GC/2003/4>.



## What are the issues and how are they human rights issues?

The fundamental right to health of children, as with adults, stems from the basic human needs that must be met in order for every individual to achieve the highest attainable standard of health, regardless of sex, race, ethnicity, ability, religion, political belief, or economic or social conditions. However, children's health rights differ from those of adults in "important normative ways."<sup>9</sup> Children of all ages are uniquely vulnerable to violations of their health rights due to "the biological and socially constructed characteristics of childhood."<sup>10</sup> This includes their developing physical and mental capacity, their dependence on adults to meet their health needs, and their changing social roles and influences, especially during the onset of puberty. As a result, children have a reduced ability to protect themselves and are more vulnerable to negative consequences of violations of their right to health:

*The physical and psychological effects that children suffer... will generally be greater than those experienced by adults due to their lower level of physical and mental development. This is true both in relation to (a) the immediate impact that violations of the right to health may have on a child's physical and psychological state, and (b) the long-term detrimental effects on the child's development and future capacity for autonomy resulting from such a violation.*<sup>11</sup>

Because children rely on adults for their growth and development, they have historically been treated as passive beings requiring "positive intervention on their behalf to ensure the realization of their rights."<sup>12</sup> As such children are "an anomaly in the liberal legal order" which otherwise views rights-holders as autonomous individuals capable of exercising free choice.<sup>13</sup> A central concern of children's health right advocates is therefore to promote children's agency and capacity for autonomy.<sup>14</sup> A key component is including children, particularly during adolescence, in decision-making processes about their health, not only with respect to their individual health but also at the systematic level of health policy and service delivery.<sup>15</sup>

International and regional human rights instruments protecting the health rights of children have articulated respect for what are known as the "four Ps": "participation by children in decisions affecting them; protection of children against discrimination and all forms of neglect and exploitation; prevention of harm to them; and provision of assistance to children for their basic needs."<sup>16</sup> The participation of children must be meaningful and should proceed "in a manner consistent with their evolving capacities."<sup>17</sup> This requires careful balancing of child protection considerations with efforts to promote the agency and decision-making potential of all children.

9 Nolan A, Yamin AE and Meier BM, *Submission on the Content of a Future General Comment on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art. 24)* (OHCHR). [http://www2.ohchr.org/english/bodies/crc/calls/submissionsCRC\\_received.htm](http://www2.ohchr.org/english/bodies/crc/calls/submissionsCRC_received.htm).

10 Nolan A, "The Child's Right to Health and the Courts," in Harrington J and Stuttaford M, eds., *Global Health and Human Rights: Legal and Philosophical Perspectives* (London: Routledge, 2010).

11 Ibid.

12 Ibid.

13 Ezer T, "A Positive Right to Protection for Children," *Yale Human Rights and Development Law Journal* 7 (2004): 1-2.

14 Nolan A, "The Child's Right to Health and the Courts," in Harrington J and Stuttaford M, eds., *Global Health and Human Rights: Legal and Philosophical Perspectives* (London: Routledge, 2010).

15 Nolan A, Yamin AE and Meier BM, *Submission on the Content of a Future General Comment on the Right of the Child to the Enjoyment of the Highest Attainable Standard of Health (art. 24)* (OHCHR). [http://www2.ohchr.org/english/bodies/crc/calls/submissionsCRC\\_received.htm](http://www2.ohchr.org/english/bodies/crc/calls/submissionsCRC_received.htm).

16 Zeldin W, "Children's Rights: International Laws," Law Library of Congress. [www.loc.gov/law/help/child-rights/international-law.php#fg](http://www.loc.gov/law/help/child-rights/international-law.php#fg). citing Van Bueren, G, *The International Law on the Rights of the Child* (Dordrecht/Boston/London, Martinus Nijhoff Publishers, 1995).

17 UN Committee on the Rights of the Child, *General Comment No. 12: The right of the child to be heard, CRC/C/GC/12* (2009). <http://www2.ohchr.org/english/bodies/crc/comments.htm>.

## Right to Life, Survival and Development

In 2011, there were an estimated 7.6 million deaths of children under 5,<sup>18</sup> with more than 70 percent due to preventable causes such as diarrhoea, pneumonia, and malnutrition.<sup>19</sup> Another 200 million children under 5 do not achieve their full developmental potential due to poverty, inequality, and inadequate opportunities for learning.<sup>20</sup> Adolescents, in particular, experience a high burden of neuropsychiatric disorders (including depression and substance abuse), violence and accidents, maternal conditions, and infectious disease.<sup>21</sup> Reducing the mortality and morbidity of children and adolescents is a key priority of the international community.<sup>22</sup> Article 6 of the CRC imposes on States a positive obligation to “improve perinatal care for mothers and babies, reduce infant and child mortality, and create conditions that promote the wellbeing of all young children during this critical phase of their lives.”<sup>23</sup> This obligation is further elaborated in Article 24, which secures the right to the highest attainable standard of health.

The health of children also reflects more broadly on the social and economic conditions in a community.<sup>24</sup> In 2011, a child born in the developing world was eight times more likely to die in childhood than her counterpart in the developed world.<sup>25</sup> Similarly, children living in countries with greater socioeconomic inequality have poorer health outcomes, with mortality associated with income inequality.<sup>26</sup> Both the CRC Committee and the CESCR regularly express concern over failed or insufficient efforts by State parties to reduce child mortality, and have also drawn attention to disparity among certain groups of children such as indigenous children,<sup>27</sup> or children living in rural or remote areas<sup>28</sup> who are more vulnerable to violations of their right to life, survival and development.

## Right to Non-Discrimination

Freedom from discrimination in access to health care, nutrition, adequate standards of living, and education, ensures that all children are equally positioned to attain their maximum level of health and development. However, given their relative dependence on others to realize their human rights, children are at heightened risk of discrimination. Children can face discrimination based on their age and status in society, but also as members of particular groups. Children belonging to minority groups, indigenous communities, and girls generally are more likely to suffer discrimination in accessing their right to health.

18 UNICEF, *State of the World's Children 2012: Children in an Urban World* (2012): 83. [www.unicef.org/sowc2012/fullreport.php](http://www.unicef.org/sowc2012/fullreport.php).

19 UNICEF, “Reduce Child Mortality,” *Millennium Development Goals*. [www.unicef.org/mdg/childmortality.html](http://www.unicef.org/mdg/childmortality.html).

20 Walker SP et al, “Inequality in early childhood: risk and protective factors for early child development,” *The Lancet* 378 (2011): 1325–38.

21 Sawyer S et al, “Adolescence: a foundation for future health,” *The Lancet* 379 (2012): 1630–40; Gore FM et al, “Global burden of diseases in young people aged 10–24 years: a systematic analysis,” *The Lancet* 377 (2011): 2093–102.

22 UN Inter-Agency and Expert Group on MDG Indicators, *The Millennium Development Goals Report* (2010). [www.un.org/millenniumgoals/pdf/MDG%20Report%202010%20En%2015%20-low%20ores%2020100615%20-.pdf#page=28](http://www.un.org/millenniumgoals/pdf/MDG%20Report%202010%20En%2015%20-low%20ores%2020100615%20-.pdf#page=28).

23 UN Committee on the Rights of the Child, *General Comment No. 7: Implementing Child Rights in Early Childhood*, CRC/C/GC/7/Rev.1 (2006).

24 UN Inter-agency Group for Child Mortality Estimation, *Levels & Trends in Child Mortality*, Report 2011 (2011). [www.who.int/maternal\\_child\\_adolescent/documents/childmortality\\_booklet\\_2011.pdf](http://www.who.int/maternal_child_adolescent/documents/childmortality_booklet_2011.pdf).

25 Nolan A, “The Child’s Right to Health and the Courts” in J Harrington and M Stuttford, eds., *Global Health and Human Rights: Legal and Philosophical Perspectives* (Routledge, 2010): 135-162. [www.routledge.com/books/details/9780415479387](http://www.routledge.com/books/details/9780415479387).

26 Viner RM et al, “Adolescence and the social determinants of health,” *The Lancet* 379 (2012): 1641–52.

27 UN Committee on the Rights of the Child, *Concluding Observations (COs) on Costa Rica - CRC/C/CRI/CO/4*, para. 29 (2011); *Panama CRC/C/PAN/CO/3-4*, para. 54 (2011).

28 UN Committee on the Rights of the Child, *Concluding Observations on Argentina, CRC/C/ARG/CO/3-4*, para. 57 (2010); *Egypt, CRC/C/EGY/CO/3-4*, para. 62 (2011); and *Bukina Faso, CRC/C/BFA/CO/3-4*, para. 54 (2010).

Article 2 of the CRC enshrines this right to non-discrimination of children, and the CRC Committee has articulated its concern over such violations of the right as:

- Social exclusion and discrimination of children from ethnic minority backgrounds or indigenous children, resulting in disparities of health outcomes.<sup>29</sup>
- A lack of culturally appropriate services, including the availability of social and health services adapted to culture, history and languages of minority and indigenous children.<sup>30</sup>
- Discrimination against girls that restricts their capacity to contribute positively to society, such as selective abortion, genital mutilation, neglect and infanticide, including through inadequate feeding in infancy.<sup>31</sup>

To fulfil their obligation to non-discrimination of children, States must work “actively to identify individual children and groups of children the recognition and realization of whose rights may demand special measures,” which may require changes in legislation, administration and resource allocation, as well as educational measures to change attitudes.<sup>32</sup>

## Right to Express Views and Have Them Taken into Account

Children are regularly denied the opportunity to be heard and to express their views freely on matters that affect their health and well-being. Yet the right of children to be heard and to participate is one of the fundamental values of the CRC, as it reiterates the understanding that the child is a fully fledged person having the right to express his or her own views in all matters affecting him and her, and having those views heard and given due weight.<sup>33</sup> It is also a right that is often infringed not only by legislation and policy that imposes age limits on the right to be heard, but also by socio-attitudinal contexts that prevent children from expressing their views in a variety of forums. Under the CRC, States are required to take all appropriate measures to ensure that the child’s “freedom to express views and the right to be consulted in matters that affect him or her is implemented from the earliest stage in ways appropriate to the child’s capacities, best interests, and rights to protection from harmful experiences.”<sup>34</sup>

The notion of “evolving capacities” is critical to the realization of this right, particularly with regard to health care, and indicates that there is no single point in development at which all children can or cannot form and articulate their views about their well-being or best interests. This recognition demands that parents, and where necessary, communities, provide “appropriate direction and guidance” in a way that does not undermine the ability of the child to exercise his or her rights.<sup>35</sup> However, the CRC Committee also goes further and calls on States to introduce legislation or regulations to ensure that children have access to confidential medical counselling and advice without parental consent, irrespective of the child’s age, where this is needed for the child’s safety or well-being.

29 Noting discrimination against Roma children in Bulgaria, Serbia, and Italy in particular with regard to access to education, health care and housing. UN Committee on the Rights of the Child, *CRC/C/SR.1318, para. 24* (2008); *CRC/C/SRB/CO/1, para. 25* (2008); *CRC/C/ITA/CO/3-4, para. 24* (2012).

30 Calling on Panama to ensure that indigenous and Afro-Panamanian girls and boys receive health services and education adapted to their culture, history and languages. CRC Committee, *Concluding Observations on Panama, CRC/C/PAN/CO/3-4, para. 81* (2011).

31 UN Committee on the Rights of the Child, *General Comment No. 7: Implementing Child Rights in Early Childhood, CRC/C/GC/7/Rev.1* (2006). On examining the gender discrimination against girls and incidence of child marriage, prostitution, and sexual abuse in India: Singh K and Kapur D, “Law, Violence and the Girl Child,” *Health and Human Rights Journal* 5, no. 2 (2001). [www.hhrjournal.org/archives-pdf/4065363.pdf.bannered.pdf](http://www.hhrjournal.org/archives-pdf/4065363.pdf.bannered.pdf).

32 UN Committee on the Rights of the Child, *General Comment No. 5: General Measures of Implementation of the Convention on the Rights of the Child*, arts. 4, 42, and 44; para. 6, *CRC/GC/2003/5* (2003).

33 UN Office of the High Commissioner for Human Rights, *Manual on Human Rights Reporting* (1997): 427. [www.ohchr.org/Documents/Publications/manualhrren.pdf](http://www.ohchr.org/Documents/Publications/manualhrren.pdf).

34 UN Committee on the Rights of the Child, *General Comment No. 7: Implementing Child Rights in Early Childhood, CRC/C/GC/7/Rev.1* (2006). <http://www2.ohchr.org/english/bodies/crc/comments.htm>.

35 Convention on the Rights of the Child, art 5. See also Viner RM et al, “Adolescence and the social determinants of health,” *The Lancet* 379 (2012): 1641–52.

If access to advice and information is conditioned on age, children cannot realize their right to make and freely express informed decisions. As such, and in terms of health care, Article 12 of the CRC obligates State Parties to provide all children with information about proposed treatments and their effects and outcomes, including in appropriate formats and accessible to children with disabilities.<sup>36</sup> The CRC Committee has explained that in order for adolescents to be able to safely and properly exercise this right “public authorities, parents and other adults working with or for children need to create an environment based on trust, information sharing, the capacity to listen and sound guidance that is conducive for adolescents’ participating equally including in decision-making processes.”<sup>37</sup>

## Right to Information; Right to Sexual and Reproductive Health and Education, including HIV

Children often lack adequate access to information and services necessary to ensure sexual health, including information related to HIV prevention and care. Critical to youth attaining the highest standard of health and developing in a well-balanced manner is having access to adequate information upon which to understand and make appropriate decisions concerning their well-being. Though children are guaranteed the right to such information under international human rights law,<sup>38</sup> often neither health information nor health services are made available, particularly with regard to sexual health. Access to sexual and reproductive services is particularly necessary for the well-being of adolescents, as adolescence is the period when many children begin to explore their sexuality.<sup>39</sup> And with 3.4 million children under the age of 15 living with HIV, and teenage pregnancies claiming the lives of young mothers and their children at a substantially higher rate than older mothers, the responsibility of states to provide comprehensive education and information about sexual and reproductive health as well as opportunities to develop the skills necessary for HIV prevention is urgent and critical.<sup>40</sup>

Where children are denied appropriate health services, including child-sensitive and confidential counselling services, and access to contraceptives, States have failed to uphold their obligation to develop preventive health care. States are responsible for ensuring that sex-education programs exist both inside and outside of school settings, and that efforts are made to raise awareness about the prevention of early pregnancy and the control of sexually transmitted diseases including HIV. The International Guidelines on HIV/AIDS and Human Rights emphasize that “the provision of these services [counseling, testing, and prevention measures] to children/adolescents should reflect the appropriate balance between the rights of the child/adolescent to be involved in decision-making according to his or her evolving capabilities and the rights and duties of parents/guardians for the health and well-being of the child.”<sup>41</sup> As such, states must also make efforts to empower parents with information about sexual health and HIV transmission, and effective measures should be taken to counter stigma and discrimination faced by children and families infected and affected by HIV.

36 UN Committee on the Rights of the Child, *General Comment No. 12: The right of the child to be heard*, CRC/C/GC/12 (2009). <http://www2.ohchr.org/english/bodies/crc/comments.htm>.

37 UN Committee on the Rights of the Child, *General Comment No. 4: Adolescent Health*, CRC/C/GC/4 (2003). <http://www2.ohchr.org/english/bodies/crc/comments.htm>.

38 Convention on the Rights of the Child, arts. 24, 13, and 17.

39 UNICEF, *Progress for Children: A report card on adolescents* (2012). [www.childinfo.org/files/PFC2012\\_A\\_report\\_card\\_on\\_adolescents.pdf](http://www.childinfo.org/files/PFC2012_A_report_card_on_adolescents.pdf).

40 World Health Organization, “Treatment of children living with HIV.” [www.who.int/hiv/topics/paediatric/en/index.html](http://www.who.int/hiv/topics/paediatric/en/index.html).

41 UNAIDS, *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version* (2006). [http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pubo7/jc1252-internguidelines_en.pdf).

## Right to Education

Today, 67 million children remain out of school. In sub-Saharan Africa alone, 10 million children drop out every year.<sup>42</sup> Ensuring universal access to primary education, a cornerstone for the development of individuals and communities, was recognized as one of eight UN Millennium Goals in 2000 (goals which all UN Member States have agreed to try to achieve by 2015). Education ends cycles of poverty and disease, and equips boys and girls with the necessary skills to confront challenges, adopt healthy lifestyles, and “take an active role in social, economic and political decision-making as they transition to adolescence and adulthood.”<sup>43</sup> Education is guaranteed to all children as a fundamental human right in the Universal Declaration for Human Rights (UDHR), the CRC, and the International Convention on Economic, Social and Cultural Rights (ICESCR). Additionally, the International Convention on the Elimination of Racial Discrimination (ICERD) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) both secure and emphasize the right of equal access to education for all.

And yet, millions of children are denied the right, with certain children (girls, children in remote areas, children from minority groups and children with disabilities) more likely to be excluded from both primary and secondary education. Under international law, states bear the responsibility for ensuring the realization of this right, and advocates have developed “right to education indicators” which aim to measure the extent to which States fulfill their legal human rights obligation. The indicators are divided into four interrelated categories: availability, accessibility, acceptability and adaptability.<sup>44</sup>

*First, availability examines whether education is generally available. Second, accessibility focuses on the various obstacles in accessing education. Third, acceptability evaluates the various aspects of the content of education. Fourth, adaptability examines whether education is adapted to the needs of various categories of persons.*<sup>45</sup>

According to both the CRC and the ICESCR, primary education should be compulsory and available free to all;<sup>46</sup> and thus, any legislation or State policy that restricts access for any child, either by the imposition of school fees, or failure to provide schools in certain areas or for certain populations, is a violation of the availability and accessibility of this fundamental right.<sup>47</sup> UN human rights treaty bodies have found violations of the acceptability of education where education is not provided in an appropriate language,<sup>48</sup> or where the curriculum fails to include education programs on the culture of ethnic, linguistic, or religious minority groups.<sup>49</sup> As the right to education is also guaranteed to traditionally excluded groups such as minorities, children with disabilities, and children in detention, States must ensure that schooling options can be adapted to meet their unique needs.

## Freedom from Abuse, Torture and Ill-Treatment

All children have a right to health and to be free from violence, abuse and neglect, yet each year, millions of children are victims of violence, abuse, and neglect, with far-reaching harm to their physical and mental health and development. Children in every country in the world are threatened by violence, where it is

42 UNICEF, “Basic Education and Gender Equality: The Big Picture.” [www.unicef.org/education/bege\\_59826.html](http://www.unicef.org/education/bege_59826.html).

43 UNICEF, “Basic Education and Gender Equality: Introduction.” [www.unicef.org/education/index\\_1.php](http://www.unicef.org/education/index_1.php).

44 Right to Education Project, “Right to Education Indicators.” [www.right-to-education.org/node/860](http://www.right-to-education.org/node/860); the 4A framework was developed by Katarina Tomaševski, the former UN Special Rapporteur on the right to education.

45 de Beco G, *Right to Education Indicator based on the 4 A framework: Concept Paper*, (The Right to Education Project, 2009). [www.right-to-education.org/sites/r2e.gn.apc.org/files/Concept%20Paper.pdf](http://www.right-to-education.org/sites/r2e.gn.apc.org/files/Concept%20Paper.pdf).

46 Convention on the Rights of the Child, art. 28; International Covenant on Economic, Social and Cultural Rights, arts. 13 and 14.

47 UN Committee on the Rights of the Child, *Concluding Observations on Panama*, CRC/C/PAN/CO/3-4, para. 62 (a) (2011).

48 Committee on the Elimination of Racial Discrimination (CERD), *Concluding Observations on Norway*, CERD/C/NOR/CO/19-20 (2011); *Denmark*, CERD/C/DNK/CO/18-19 (2010); *Vietnam*, CERD/C/VNM/CO/10-14 (2012).

49 UN Committee on the Rights of the Child, *Concluding Observations on Costa Rica*, CRC/C/CRI/CO/4, paras. 67, 69 (2011).



often socially approved, and frequently legal and State sanctioned.<sup>50</sup> In 2006, the UN conducted the first global study on all forms of violence against children in various settings: family, school, alternative care institutions, detention centers and communities. It found that States often fail to take sufficient measures to protect children from domestic violence, corporal punishment, and/or other forms of abuse and neglect, and that such maltreatment is often justified by adults as “tradition” or “disguised as ‘discipline.’”<sup>51</sup>

Though accurate statistics are hard to ascertain, the UN study estimated that there were 53,000 childhood homicides in 2006.<sup>52</sup> Child deaths from maltreatment only represent a small fraction of the problem of child abuse and neglect, with some international studies having shown that, in some parts of the world, between a quarter and a half of all children report severe and frequent physical abuse.<sup>53</sup> In 2002, 150 million young girls suffered forced sexual intercourse or other forms of sexual violence.<sup>54</sup> And among their peers, children with disabilities are particularly vulnerable to abuse and neglect.

Preventing such abuse and violence against all children is a positive obligation of States. Article 19 of the CRC instructs, “States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.” Children have a right to increased protection from maltreatment given the vulnerabilities inherent in their age and dependence on adults for care and security. As such, in cases of abuse, the child explicitly “has the right to the protection of the law against such interference or attacks.”

The CRC Committee considers the absence of legislation protecting children from domestic violence to be a violation of the obligation of States under Article 19. State Parties are often called to implement legislation that criminalizes domestic violence,<sup>55</sup> and absolutely prohibits corporal punishment in all settings. In General Comment 8, the CRC Committee emphasizes that “eliminating violent and humiliating punishment of children, through law reform and other necessary measures, is an immediate and unqualified obligation of States parties.”<sup>56</sup>

Preventing physical and psychological abuse and violence against children has rightfully become a key priority of the international community, particularly as such maltreatment is associated with risk factors and risk-taking behaviors later in life.<sup>57</sup> According to some studies, these include “violent victimization and the perpetration of violence, depression, smoking, obesity, high-risk sexual behaviours, unintended pregnancy, and alcohol and drug use. Such risk factors and behaviors can lead to some of the principal causes of death, disease and disability: as heart disease, sexually transmitted diseases, cancer, and suicide.”<sup>58</sup>

50 UN General Assembly, *Report of the independent expert for the United Nations study on violence against children*, A/61/299 (2006).

51 Ibid. at 5.

52 Ki-Moon B, *Children and the Millennium Development Goals: Progress towards a World Fit for Children* (UNICEF, 2006): 53. [www.unicef.org/publications/files/Children\\_and\\_the\\_MDGs.pdf](http://www.unicef.org/publications/files/Children_and_the_MDGs.pdf).

53 World Health Organization and International Society for Prevention of Child Abuse and Neglect, *Preventing Child Maltreatment: A guide to taking action and generating evidence* (2006). [http://c.ymcdn.com/sites/www.ispcan.org/resource/resmgr/docs/preventing\\_child\\_maltreatment.pdf](http://c.ymcdn.com/sites/www.ispcan.org/resource/resmgr/docs/preventing_child_maltreatment.pdf).

54 Ki-Moon B, *Children and the Millennium Development Goals*, 59.

55 UN Committee on the Rights of the Child, *Concluding Observations on Algeria*, CRC/C/DZA/CO/3-4, para. 45 (2012), and *Burkina Faso*, CRC/C/BFA/CO/3-4, para. 50 (2010).

56 UN Committee on the Rights of the Child, *General Comment No. 8: The right of the child to protection from corporal punishment and other cruel or degrading forms of punishment*, CRC/C/GC/8, arts. 19; 28, para. 2; and 37, inter alia (2006).

57 Kydd JW, “Preventing Child Maltreatment: An Integrated Multisectoral Approach,” *Health and Human Rights Journal* 6, no. 2 (2003).

58 World Health Organization and International Society for Prevention of Child Abuse and Neglect. *Preventing Child Maltreatment: A guide to taking action and generating evidence* (2006). [http://c.ymcdn.com/sites/www.ispcan.org/resource/resmgr/docs/preventing\\_child\\_maltreatment.pdf](http://c.ymcdn.com/sites/www.ispcan.org/resource/resmgr/docs/preventing_child_maltreatment.pdf).

## Freedom from Economic or Sexual Exploitation

Children have the right to be protected from any form of exploitation that may harm their physical, mental, and social development and interfere with their right to education. There are an estimated 250 million child laborers globally. Worldwide, approximately 1.2 million children and adolescents are trafficked for economic and sexual exploitation each year.<sup>59</sup> States are responsible for ensuring that children are not exposed to hazardous circumstances that may jeopardize their health, safety, and well-being. The CRC devotes several articles to preventing exploitation, with Article 32 protecting the child from economic exploitation, Article 34 protecting children from sexual exploitation, Article 35 providing protection from trafficking, and Article 36 protecting children against all other forms of exploitation. Where children are recruited into dangerous industries, where minimal ages of employment are lower than ages of compulsory schooling, or where limited action is taken by States to prosecute child traffickers, States are failing to uphold their international human rights obligations.<sup>60</sup>

Children belonging to vulnerable groups are often at heightened risk for exploitation. As such, human rights treaty bodies as well as various independent experts frequently call on States to improve living conditions, educational opportunities, and vocational training programs for such young people so as to mitigate the potential that they may be forced (either directly or indirectly) into dangerous economic or sexual circumstances.<sup>61</sup> States are given some measure of flexibility in determining minimum age of employment,<sup>62</sup> and both scholars and human rights mechanisms recognize subjectivity in the term “exploitative” and the need to balance regulations with the child’s right to participation and decision-making.<sup>63</sup> However, freedom from sexual abuse and exploitation is clearly and fully protected and recent international instruments have established further measures that States should undertake in order to guarantee the protection of all children, and especially those at heightened risk, from any sexual exploitation and all worst forms of child labor.

In 1999, the International Labour Organization, a specialized UN agency responsible for setting and monitoring international labor standards, adopted the Convention Concerning the Prohibition and Immediate Action for the Elimination of the Worst Forms of Child Labour. The Convention seeks urgent and effective measures to eliminate slavery, child prostitution, child involvement in illicit activities, and any work that is likely to harm the health, safety, or morals of children.<sup>64</sup> Children are further protected against exploitation by the Optional Protocol on the sale of children, child prostitution and child pornography (OPSC), which entered into force in 2002. The OPSC criminalizes specific acts relating to the sale of children, child prostitution and child pornography, including attempt and complicity. It lays down minimum standards for protecting child victims in criminal justice processes and recognizes the right of victims to seek compensation.<sup>65</sup>

59 International Labour Organization (ILO), *A Future Without Child Labour: Global Report* (2002).

60 UN Committee on the Rights of the Child, *inter alia* *Concluding Observations on Burkina Faso* CRC/C/BFA/CO/3-4, para. 68 (2010); *Singapore* CRC/C/SGP/CO/2-3, para. 62 (2010), para. 62; see also CESCR, *Concluding Observations on Sri Lanka* E/C.12/LKA/CO/2-4 (2010).

61 UN General Assembly, *Recommendations of the Special Rapporteur on the Sale of Children, Child Prostitution and Child Pornography on Greece*, E/CN.4/2006/67/Add.3 (2006) and the *United Arab Emirates*, A/HRC/16/57/Add.2 (2010).

62 International Labour Organization, *Convention No. 138 related to the minimum age of employment*, art 7(1) (1973, entry into force 19 June 1967).

63 For discussion on the subjectivity of “exploitation” and the challenge of defining child labour within a human rights context, see Parker DL and Bachman S, “Economic Exploitation and the Health of Children: Towards a Rights-Oriented Public Health Approach,” *Health and Human Rights Journal* 5, no. 2 (2001).

64 International Labour Organization, *Convention No. 182 on the Worst Forms of Child Labour*, (1999, entry into force on 19 Nov 2000). [www.ilo.org/dyn/normlex/en/f?p=1000:12100:0::NO::P12100\\_INSTRUMENT\\_ID:312327](http://www.ilo.org/dyn/normlex/en/f?p=1000:12100:0::NO::P12100_INSTRUMENT_ID:312327).

65 Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography, G.A. Res. 54/263, Annex II, 54 U.N. GAOR Supp. (No. 49) at 6, U.N. Doc. A/54/49, Vol. III (2000, entry into force 18 January 2002). <http://www2.ohchr.org/english/law/crc-sale.htm>.



In spite of these efforts, exploitation of children continues to exist on a massive scale, and though child labor is a complex issue, the potential costs of denying children's rights to protection from exploitation are enormous and unacceptable.<sup>66</sup> In addition to the harm intrinsic to economic and sexual exploitation, children can suffer long-term social, emotional, and cognitive impairments, as well as behaviors that cause disease, injury and social problems.<sup>67</sup> States are encouraged to take deliberate and swift action to put in place legislative and policy measures that explicitly identifies and prohibits the exploitation of children, and also to employ a holistic framework that aims to guarantee the safe upbringing, well-being, and development of all children.

## Freedom from Harmful Traditional Practices

Children are protected under international human rights law from harmful cultural traditions, and all practices that can have a negative affect on their health and well-being. For example, according to a WHO estimate, between 100 and 140 million girls and women in the world have undergone some form of female genital mutilation (FGM).<sup>68</sup> Though "harmful traditional practices" is a term most frequently associated with FGM and other practices targeting young girls such as forced marriages and preferential treatment of sons, there are many other harmful practices against both boys and girls.<sup>69</sup> The international community has been historically wary to intervene to prevent harmful traditional practices, viewing such practices as culturally sensitive issues. However, there has been noticeable progress in human rights protection against value or belief-based practices that have an undeniably harmful impact on the child or adolescent victim. The WHO writes:

*It is unacceptable that the international community remain passive in the name of a distorted vision of multiculturalism. Human behaviors and cultural values...have meaning and fulfill a function for those who practice them. However, culture is not static but it is in constant flux, adapting and re-forming. People will change their behavior when they understand the hazards and indignity of harmful practices and when they realize that it is possible to give up harmful practices without giving up meaningful aspects of their culture.<sup>70</sup>*

A human rights perspective towards harmful traditional practices affirms the rights of children to physical and mental integrity, freedom from discrimination on the basis of age of gender, and to the highest standard of health. Thus, states are required under the CRC, CEDAW, and the International Covenant on Civil and Political Rights (ICCPR) to take action to end such harmful traditional practices. The corresponding human rights treaty bodies hold States accountable for taking measures to prevent such practices and guarantee that culture is not used as a justification for the violation of the health and human rights of children.<sup>71</sup>

66 UN Study on Violence against Children, *Chapter 6: Violence against children in places of work*. [www.unicef.org/violencestudy/6.%20World%20Report%20on%20Violence%20against%20Children.pdf](http://www.unicef.org/violencestudy/6.%20World%20Report%20on%20Violence%20against%20Children.pdf).

67 UN Study on Violence against Children, *Chapter 1: An end to violence against children*. [www.unicef.org/violencestudy/1.%20World%20Report%20on%20Violence%20against%20Children.pdf](http://www.unicef.org/violencestudy/1.%20World%20Report%20on%20Violence%20against%20Children.pdf).

68 UN Study on Violence against Children, *Chapter 3: Violence Against Children in the Home and the Family*, p. 60. [www.unicef.org/violencestudy/3.%20World%20Report%20on%20Violence%20against%20Children.pdf](http://www.unicef.org/violencestudy/3.%20World%20Report%20on%20Violence%20against%20Children.pdf).

69 For a list of harmful traditional practices, see UN Committee on the Rights of the Child, *General Comment No. 13 The right of the child to freedom from all forms of violence*, CRC/C/GC/13, art 29 (2011).

70 World Health Organization, *Female Genital Mutilation: A Joint WHO/UNICEF/UNFPA Statement* (1996).

71 Convention on the Rights of the Child, art 24; Convention on the Elimination of Discrimination against Women (CEDAW), arts 5, 16; and International Covenant on Civil and Political Rights, art 7.

## What are human rights-based approaches for upholding the health rights of children?

A basic principle of child rights, as guaranteed by the CRC is to secure the best interest of the child. According to Article 3 of the CRC, the best interest of the child is to be a 'primary consideration' in all actions regarding children. The principle thus underlines all human rights-based approaches for the promotion and protection of children's health rights. The best interests of the child are to guide the implementation of the CRC by State Parties, including all "legislative, administrative and other measures" necessary to realize the human rights of children and adolescents.<sup>72</sup> The following list includes objectives and initiatives that support a child-centered, human rights-based approach that serves to prevent and/or defend against some of the violations detailed in the section above.<sup>73</sup>

### Ensuring Early Childhood Survival, Development and Well-being<sup>74</sup>

Given that most children under 5 die from one or more of five common (and treatable) conditions – diarrheal dehydration, measles, respiratory infections, malaria, or malnutrition, continuing and comprehensive efforts must be made by States to prevent such deaths. Communication of health information to families and care takers is an underlying premise of effective health interventions, particularly to secure the well being of young children. "Communication is vital: conveying to parents the key information about how to manage diarrhoea at home – or how to recognize pneumonia or malaria and seek timely care from someone with medical training – will save many children's lives."<sup>75</sup> For example, some of the most effective initiatives to reduce malnutrition were those that enabled "families to understand the causes of malnutrition and to take informed action to address them," including the promotion of breast feeding, and addressing key micronutrient deficiencies.<sup>76</sup>

### Eliminating Barriers to Education and Maximum Development

Education is also critical to the development of communities, and thus eliminating the cultural, social and economic barriers to education for girls and other vulnerable children (including poor children, children living in remote locations, children with disabilities, and children belonging to minority groups) must be a priority of any child-centered education program. However, simply eliminating barriers is insufficient; States must use strategic planning to ensure realistic progress. For example, eliminating school fees as required by the CRC has made significant impact in access to primary education for children in Eastern/Southern Africa,<sup>77</sup> where enrollment increased significantly; however, ensuring sustainable and quality education demands acquiring the funds to provide adequate accommodations, supplies, and teachers to these newly enrolled students.

<sup>72</sup> Convention on the Rights of the Child, art 4.

<sup>73</sup> UNICEF, *A World Fit for Children* (2002). [www.unicef.org/specialsession/wffc/resource.html](http://www.unicef.org/specialsession/wffc/resource.html).

<sup>74</sup> UN Committee on the Rights of the Child, *General Comment No. 7 Implementing child rights in early childhood* (2005) CRC/C/GC/7/Rev. 1. (20 September 2006).

<sup>75</sup> Annan K, *We the Children: Meeting the promises of the World Summit for Children* (UNICEF, 2001): 26. [www.unicef.org/specialsession/about/sgreport-pdf/sgreport\\_adapted\\_eng.pdf](http://www.unicef.org/specialsession/about/sgreport-pdf/sgreport_adapted_eng.pdf).

<sup>76</sup> Ibid.

<sup>77</sup> UNICEF, *Progress for Children: A report card on gender parity and primary education*. (2005). [www.childinfo.org/files/PFC05n2en.pdf](http://www.childinfo.org/files/PFC05n2en.pdf).

## Meaningful Participation of Young People in Decisions Affecting Their Health<sup>78</sup>

A programming approach that is guided by the CRC should create conditions that allow families with children and children themselves to participate more fully in community life and in the development of policies that affect them. Consultation with children should make explicit efforts to include vulnerable children and their families, including children of minority groups, poor children, disabled children, and girls, generally. The goal is not just to increase participation of children in decision making and health promotion but to ensure their meaningful participation. “If programmes are to meet the health needs of children it is vital that they are given some ownership of the programmes by having a voice in planning, implementing and monitoring programme activities.”<sup>79</sup>

## Supporting Parents and Strengthening Families

The CRC clearly emphasizes the obligation of governments to support parents and families in their duties as the primary caregivers and protectors of children. Under Article 3, paragraph 2, “States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.” Families have the most potential to protect children and also empower young people with tools and strategies to protect themselves. The need to strengthen family life and support families (particularly those in challenging situations) must therefore be a priority at every stage of intervention and programming. Parents and families should be provided with opportunities (such as trainings and accessible social services) to develop the skills and identify the resources they need to understand and meet their children’s needs and protect them from harm.

<sup>78</sup> UNICEF, “Child and youth participation resource guide, Participation in programme areas.” [www.unicef.org/adolescence/cypguide/index\\_health.html](http://www.unicef.org/adolescence/cypguide/index_health.html).

<sup>79</sup> Child-to-Child Trust, *New directions for child-to-child: Ideas and experiences from a consultation meeting held in Cambridge, England in March 2002* (2003): 29. [www.child-to-child.org/publications/c2creport2002.pdf](http://www.child-to-child.org/publications/c2creport2002.pdf).

## Creating National Plans of Action to Ensure the Well-being of Children

In 2002, 180 countries gathered to develop an ambitious ten-year action plan called “A World Fit for Children” (WFFC). Grounded in the principles set forth in the CRC, the WFFC agenda called on all participating countries to create national plans of action (NPA) that effectively integrated international legal standards and secured the rights of children. Where they are not in place, national strategies are often recommended by the CRC Committee and require such elements as:

1. Time-bound, measurable goals for improving protection of child rights;
2. Cooperation between government and civil society, including children;
3. Child-centered budgets and adequate resources allocation;
4. Communication and campaigns that inform the general public of child rights;
5. Regular monitoring of the situation of children at the national level and engagement with the UN human rights monitoring mechanisms.<sup>80</sup>

A comprehensive approach to child protection and development, ensures that both the root causes and consequences of violations of child rights are considered and meaningfully addressed.

## Reshaping National Laws for the Protection of Children's Health Rights

Countries around the world have undertaken reforms to bring their national legislation into closer conformity with the principles and provisions of the CRC. Such efforts that better safeguard the health rights of children include: laws to protect children from discrimination; laws to protect against domestic violence and prohibit corporal punishment; laws prohibiting forced marriage and raising the legal marriage age; and labor laws prohibiting the involvement of children in hazardous employment and other worst forms of child labor.<sup>81</sup> However, changing the law alone is insufficient to guarantee protection if efforts are not made to address the underlying social contexts that require such legislation. Thus, programs committed to achieving substantial changes in the legislative protection of the health and human rights of children must also ensure that children, parents, communities, and enforcement officials are trained and made aware of new regulations and the human rights that warrant such protection.

<sup>80</sup> UNICEF, “Follow-up: National plans of action,” *United Nations Special Session on Children 8-10 May 2002*. [www.unicef.org/specialsession/followup\\_npa/index.html](http://www.unicef.org/specialsession/followup_npa/index.html); National Children's Alliance, *The National Children's Alliance and A Rights Based Approach: Setting the Context for Discussion and Action* (2003). [www.nationalchildrensalliance.com/nca/pubs/2003/National\\_Plan\\_of\\_Action.pdf](http://www.nationalchildrensalliance.com/nca/pubs/2003/National_Plan_of_Action.pdf).

<sup>81</sup> Annan K, *We the Children: Meeting the promises of the World Summit for Children* (UNICEF, 2001): 76. [www.unicef.org/specialsession/about/sgreport-pdf/sgreport\\_adapted\\_eng.pdf](http://www.unicef.org/specialsession/about/sgreport-pdf/sgreport_adapted_eng.pdf).

## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO CHILDREN'S HEALTH?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to children's health rights. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<p><b>UN treaty body interpretation</b></p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
<b>Human rights standards</b>	<p><b>Case law</b></p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and children's health.

## Abbreviations

In the tables, we use the following abbreviations to refer to the fourteen treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention Against Torture ( <b>CAT</b> )	Committee Against Torture ( <b>CAT Committee</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
African Charter on the Rights and Welfare of the Child ( <b>ACRWC</b> )	African Committee of Experts on the Rights and Welfare of the Child ( <b>ACRWC Committee</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
Convention concerning Indigenous and Tribal Peoples in Independent Countries ( <b>ILO Con</b> )	International Labour Organization ( <b>ILO</b> )

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Life	Art. 3	Art. 6(1)				Art. 6(1)
Non-Discrimination and Equality	Art. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
Have Views Respected						Art. 12
Expression and Information	Art. 19	Art. 19(2)				Art. 13, Art. 17
Abuse, Torture, and Ill-Treatment*	Art. 5	Art. 7				Art. 37(a)
Disabilities	Art. 25					Art. 2, Art. 23
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24
Education	Art. 26		Art. 13	Art. 10	Art. 5(e) (v)	Art. 28, Art. 29
Sexual or Economic Exploitation			Art. 10(3)	Art. 6		Art. 32, Art. 34
Harmful Traditional Practices						Art. 24(3)

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

**Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Life	Art. 4	Art. 2		Art. I	Art. 4
Non-discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
Have Views Respected					
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Abuse, Torture, and Ill-Treatment	Art. 5	Art. 3			Art. 5(2)
Disabilities	Art. 18(4)		Art. 15		
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Education	Art. 17			Art. XII	
Sexual or Economic Exploitation	Art. 5	Art. 4			
Harmful Traditional Practices					



## Table I: Children's Health and the Right to Life, Survival and Development

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• High rates of maternal, neonatal and under-five mortality rates.</li> <li>• Ill-treatment, abandonment or even infanticide of children motivated by traditional beliefs.</li> <li>• High rates of child and adolescent suicide and self-harm.</li> <li>• Allowing the death penalty to be imposed for crimes committed by individuals under the age of 18.</li> <li>• Failing to protect children from violence (e.g. Mapiripán Massacre).</li> </ul>	
Human Rights Standard	Treaty Body Interpretation
<p><b>CRC 6(1):</b> States Parties recognize that every child has the inherent right to life. <b>(2)</b> States Parties shall ensure to the maximum extent possible the survival and development of the child.</p> <p><b>CRC 24(2):</b> States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures: <b>(a)</b> To diminish infant and child mortality.</p>	<p><b>CRC, General Comment 5(12):</b> The Committee expects States to interpret “development” in its broadest sense as a holistic concept, embracing the child’s physical, mental, spiritual, moral, psychological and social development. Implementation measures should be aimed at achieving the optimal development for all children. CRC/GC/2003/5 (Nov. 27, 2003).</p> <p><b>CRC, General Comment 9(31):</b> The inherent right to life, survival and development is a right that warrants particular attention where children with disabilities are concerned. In many countries of the world children with disabilities are subject to a variety of practices that completely or partially compromise this right . . . States parties are urged to undertake all the necessary measures required to put an end to these practices, including raising public awareness, setting up appropriate legislation and enforcing laws that ensure appropriate punishment to all those who directly or indirectly violate the right to life, survival and development of children with disabilities. CRC/C/GC/9 (Feb. 27, 2007).</p> <p><b>CRC Committee:</b> Expressing concern of high rates of infant mortality in <b>Djibouti</b> CRC/C/DJI/CO/2 (CRC, 2008), para. 29; neonatal deaths and premature births in <b>Georgia</b> CRC/C/GEO/CO/3 (CRC, 2008) para. 44; and maternal, neonatal and under-five mortality rates in <b>Algeria</b> CRC/C/DZA/CO/3-4 (CRC, 2012), para. 57; <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012) para. 49; <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010) para. 54; and <b>Argentina</b> CRC/C/ARG/CO/3-4 (CRC, 2010) para. 57.</p> <p><b>CRC Committee:</b> Recommending that <b>Madagascar</b> take all necessary measures to stop the ill-treatment, rejection and abandonment of twins, including through legislation and increased awareness-raising in the society at large, which should involve traditional leaders. CRC/C/MDG/CO/3-4 (CRC, 2012), para. 28.</p> <p><b>CRC Committee:</b> Expressing serious concern and recommending immediate action to avoid any future massacres of albino children in <b>Burundi</b>, including to investigate, prosecute and condemn the perpetrators of such crimes. CRC/C/BDI/CO/2 (CRC, 2010), para. 34.</p> <p><b>CRC Committee:</b> Urging research on suicide risk factors among children, both in the families of children affected and the education system in <b>Korea</b>. CRC/C/KOR/CO/3-4 (CRC, 2012), para. 30.</p> <p><b>CRC Committee:</b> Recommending <b>Argentina</b> to take effective measures to prevent child suicides and self-inflicted injuries in detention. CRC/C/ARG/CO/3-4 (CRC, 2010), para. 37.</p>

**Table I(cont.)**

Human Rights Standard	Treaty Body Interpretation
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p> <p><b>(2)</b> The steps to be taken by the States Parties . . . to achieve the full realization of this right shall include those necessary for: <b>(a)</b> The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child.</p>	<p><b>CESCR, General Comment 14(14):</b> “The provision for the reduction of the stillbirth rate and of infant mortality and for the healthy development of the child” (Art. 12.2 (a)) may be understood as requiring measures to improve child and maternal health, sexual and reproductive health services, including access to family planning, pre- and post-natal care, emergency obstetric services and access to information, as well as to resources necessary to act on that information. E/C.12/2000/4 (August 11, 2000).</p> <p><b>CESCR, General Comment 14(52):</b> Violations of the obligation to fulfill occur through the failure of States parties to take all necessary steps to ensure the realization of the right to health. Examples include the failure . . . to reduce infant and maternal mortality rates. E/C.12/2000/4 (August 11, 2000).</p> <p><b>CESCR:</b> Expressing concern over high maternal, infant and under-five mortality rates in <b>Angola</b> E/C.12/AGO/CO/3 (CESCR, 2009), para. 36; <b>Democratic Republic of Congo</b> E/C.12/COD/CO/4 (CESCR, 2009) para. 34; <b>Kenya</b> E/C.12/KEN/CO/1 (CESCR, 2008) para. 32; and <b>Morocco</b> E/C.12/1/ADD.55 (CESCR, 2000), para. 29.</p> <p><b>CESCR:</b> Recommending that <b>Benin</b> “step up its efforts to prevent and halt killings of so-called “witch children” by including provisions in criminal law to suppress this practice and organizing campaigns to heighten awareness of its criminal nature among local authorities, doctors, midwives and the population at large.” E/C.12/BEN/CO/2 (CESCR, 2008), para. 40.</p>
<p><b>ICCPR 6(1):</b> Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.</p>	<p><b>HRC:</b> Noting the very high maternal and infant mortality rates in <b>Democratic Republic of Congo</b> and <b>Mali</b> and calling for efforts to increase access to health services. CCPR/C/COD/CO/3 (HRC, 2006), para. 14, CCPR/CO/77/MLI (HRC, 2003), para. 14.</p>
<p><b>ICCPR 6(5):</b> Sentence of death shall not be imposed for crimes committed by persons below eighteen years of age.</p>	<p><b>HRC:</b> Repeating to <b>Sudan</b> that the Covenant does not allow the death penalty to be imposed for crimes committed by individuals under the age of 18, and permits no derogation from that article. CCPR/C/SDN/CO/3 (HRC, 2007), para. 20.</p>
<p><b>CEDAW 12(2):</b> States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.</p>	<p><b>CEDAW Committee:</b> Calling on the <b>Lao People's Democratic Republic</b> to prioritize reducing maternal and infant mortality rates by developing the midwifery workforce and making the services of skilled birth attendants available and accessible, including emergency obstetric delivery services, and by granting free services where necessary. CEDAW/C/LAO/CO/7 (CEDAW, 2009).</p> <p><b>CEDAW Committee:</b> Noting with concern that the maternal and infant mortality rates in <b>Timor-Leste</b> are extremely high. CEDAW/C/TLS/CO/1 (CEDAW, 2009).</p>

**Table I(cont.)**

Human Rights Standards	Case Law
<p><b>ACHR 4(1):</b> Every person has the right to have his life respected. This right shall be protected by law and, in general, from the moment of conception. No one shall be arbitrarily deprived of his life.</p> <p><b>ACHR 19:</b> Every minor child has the right to the measures of protection required by his condition as a minor on the part of his family, society, and the state.</p>	<p><b>IACHR:</b> Finding that Colombia violated the right of children under Article 19 of the American Convention, in combination with the rights to life, humane treatment and freedom of movement and residence under Articles 4(1), 5(1) and 22(1), by failing to protect the children of Mapiripán before, during and after the massacre and in connection with the displacement of many such children. Mapiripán Massacre v. Colombia, Series C No. 134 (September 15, 2005).</p>

**Table 2: Children's Health and the Right to Non-Discrimination**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Discrimination against Roma children, indigenous children, and children of other minority communities with regard to access to health care, education and housing.</li> <li>• A lack of culturally appropriate services, including social and health services and education, resulting in the discrimination against minority children.</li> <li>• Disparities in health outcomes of children on the basis of ethnic, racial, religious or geographic lines.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 2(1):</b> States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.</p>	<p><b>CRC, General Comment 5(12):</b> This non-discrimination obligation requires States actively to identify individual children and groups of children the recognition and realization of whose rights may demand special measures . . . Addressing discrimination may require changes in legislation, administration and resource allocation, as well as educational measures to change attitudes. CRC/GC/2003/5 (November 27, 2003).</p> <p><b>CRC Committee:</b> Noting persistent discrimination against Roma children in <b>Bulgaria, Serbia, and Italy</b>, in particular with regard to access to education, health care and housing. CRC/C/SR.1318 (CRC, 2008), para. 24, CRC/C/SRB/CO/1 (CRC, 2008) para. 25, CRC/C/ITA/CO/3-4 (CRC, 2012) para. 24.</p> <p><b>CRC Committee:</b> Noting that the social exclusion and structural discrimination of the Roma population in <b>Finland</b> leads to an increase in substance abuse and mental health problems, and a poor standard of living for Roma children. CRC/C/FIN/CO/4 (CRC, 2011), para. 25.</p> <p><b>CRC Committee:</b> Recommending that <b>Panama</b> take all necessary steps to address and prevent the marginalization and discrimination of indigenous and Afro-Panamanian girls and boys; that they receive health services and education adapted to their culture, history and languages; and that they enjoy an adequate standard of living. CRC/C/PAN/CO/3-4 (CRC, 2011) para. 81.</p> <p><b>CRC Committee:</b> Expressing concern that Batwa children in <b>Burundi</b> suffer from discrimination in relation to the enjoyment of their rights, including the rights to health care, food, survival and development. CRC/C/BDI/CO/2 (CRC, 2010), para. 78.</p> <p><b>CRC Committee:</b> Expressing concern that there are growing disparities affecting indigenous children in <b>Costa Rica</b> with regard to access to health care, especially in rural and coastal areas. Child mortality of indigenous children is twice as high as the national average. CRC/C/CRI/CO/4 (CRC, 2011), para. 29.</p> <p><b>CRC Committee:</b> Calling on <b>Syria</b> to repeal legal provisions that discriminate against girls, and take all the necessary measures to eliminate societal discrimination against them through public educational programs, including campaigns organized in cooperation with opinion leaders, families and the media to combat the stereotyping of gender roles. CRC/C/SYR/CO/3-4 (CRC, 2012) para. 32.</p> <p><b>CRC Committee:</b> Recommending that <b>Norway</b> “make every effort to ensure that children from ethnic minority backgrounds and indigenous children have equal access to all children's rights, including access to welfare, health services and schools ...” CRC/C/NOR/CO/4 (CRC, 2010).</p> <p><b>CRC Committee:</b> Recommending that the <b>Philippines</b> “implement policies and programmes in order to ensure equal access for indigenous and minority children to culturally appropriate services, including social and health services and education.” CRC/C/PHL/CO/3-4 (CRC, 2009).</p>

**Table 2 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICERD 2:</b> States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races.</p> <p><b>ICERD 5:</b> In compliance with the fundamental obligations laid down in article 2 of this Convention, States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights: (e) (iv) The right to public health, medical care, social security and social services.</p>	<p><b>CERD:</b> Recommending that <b>Costa Rica</b> make strenuous efforts to combat child mortality in the indigenous communities (art. 5 (iv)). A/62/18 (CERD, 2007).</p> <p><b>CERD:</b> Expressing concern that discrepancies still remaining in <b>Israel</b> between infant mortality rates and life expectancy rates of Jewish and non-Jewish populations, and fact that minority women and girl children are often most disadvantaged. CERD/C/ISR/CO/13 (CERD, 2007).</p> <p><b>CERD:</b> Expressing concern that the Roma community in <b>Romania</b> continue to be the targets of racial stereotyping and racial discrimination in access to education and in the quality of education — including through segregation of Roma children — as well as in access to housing, care, health services, social services and employment. CERD/C/ROU/CO/16-19 (CERD, 2010).</p> <p><b>CERD:</b> Expressing concern that children from indigenous or tribal groups in <b>Suriname</b> continue to experience discrimination in, inter alia, access to education, health and public services. CERD/C/SUR/CO/12 (CERD, 2009).</p>
<p><b>CEDAW 2:</b> States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women.</p>	<p><b>CEDAW Committee:</b> Noting the multiple forms of discrimination faced by Roma women and girls in <b>Romania</b>, who remain marginalized with regard to their education, health, housing, employment, and participation in political and public life. CEDAW/C/ROM/CO/6 (CEDAW, 2006), para. 26.</p>
<p><b>ICESCR 2(2):</b> The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status.</p>	<p><b>CESCR:</b> Recommending that <b>Benin</b> consider amending the Personal and Family Code with a view to guaranteeing full equality between children born in and out of wedlock and remove the phrase “legitimate children” from legal language. E/C.12/BEN/CO/2 (CESCR, 2008).</p> <p><b>CESCR:</b> Expressing concern that despite legislative changes designed to ensure equal treatment of children, de facto discrimination against children born out of wedlock is widespread in <b>Uruguay</b>. E/C.12/URY/CO/3-4 (CESCR, 2010).</p>

**Table 3: Children's Health and the Right to Have His or Her Views Respected**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>Failing to enshrine the child's right to express his or her own views and the opportunity to be heard into domestic law and policy.</li> <li>Socio-attitudinal contexts that prevent children from expressing their views.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 12(1):</b> States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.</p> <p><b>CRC 12(2):</b> For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.</p>	<p><b>CRC General Comment 5(12):</b> If consultation is to be meaningful, documents as well as processes need to be made accessible. But appearing to “listen” to children is relatively unchallenging; giving due weight to their views requires real change. Listening to children should not be seen as an end in itself, but rather as a means by which States make their interactions with children and their actions on behalf of children ever more sensitive to the implementation of children's rights. CRC/GC/2003/5 (November 27, 2003).</p> <p><b>CRC Committee:</b> Recommending that <b>Bhutan:</b> (a) Promote and facilitate, within the family and in schools as well as in judicial and administrative proceedings, respect for the views of children and their participation in all matters affecting them, in accordance with their ability to form their own views and in accordance with their age and maturity; (b) Develop a systematic approach to increase public awareness of the participatory rights of children and encourage respect for the views of children within the family, school, care institutions, monasteries, community and the administrative and judicial system; CRC/C/SR.1369 (CRC, 2008) para. 30.</p> <p><b>CRC Committee:</b> Expressing concern that there has been little progress in the <b>United Kingdom</b> in enshrining Article 12 in education law and policy. CRC/C/GBR/CO/4 (CRC, 2008).</p> <p><b>CRC Committee:</b> Expressing concern that socio/traditional-attitudinal context in the <b>Republic of Korea</b> and <b>Singapore</b> limit, or prevent, children from expressing their views on a wide range of issues that affect them within the family, schools, institutions, judicial system and society at large. CRC/C/KOR/CO/3-4 (CRC, 2012) para. 34, CRC/C/SGP/CO/2-3 (CRC, 2010) para. 33.</p>

**Other Interpretations**

**Charter of Fundamental Rights of the European Union (24) 1** Children shall have the right to such protection and care as is necessary for their well-being. They may express their views freely. Such views shall be taken into consideration on matters which concern them in accordance with their age and maturity.

**Table 4: Children's Health and the Right to Information**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Limited access to health information, particularly reproductive health for adolescents.</li> <li>• Information is disseminated in a language that most children do not understand.</li> <li>• Official censorship on media that restricts the right of children to appropriate information.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 13:</b> The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.</p>	<p><b>CRC General Comment 12(100):</b> Children, including young children, should be included in decision-making processes, in a manner consistent with their evolving capacities. They should be provided with information about proposed treatments and their effects and outcomes, including in formats appropriate and accessible to children with disabilities. CRC/C/GC/12 (July 20, 2009).</p> <p><b>CRC General Comment 12(81):</b> Freedom of expression relates to the right to hold and express opinions, and to seek and receive information through any media. It asserts the right of the child not to be restricted by the State party in the opinions she or he holds or expresses. As such, the obligation it imposes on States parties is to refrain from interference in the expression of those views, or in access to information, while protecting the right of access to means of communication and public dialogue. CRC/C/GC/12 (July 20, 2009).</p> <p><b>CRC Committee:</b> Recommending increased information and education with respect to adolescent sexual and reproductive health in the <b>United Kingdom</b> CRC/C/GBR/CO/4 (CRC, 2008), para. 61; <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 55; <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), para. 47; <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 52; and <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), para. 63.</p> <p><b>CRC Committee:</b> Expressing concern that in <b>Algeria</b> sexual and reproductive health services for adolescents are scarce and that sexual and reproductive health education remains underdeveloped. The Committee is also concerned that knowledge of HIV transmission and prevention is low among adolescents. CRC/C/DZA/CO/3-4 (CRC, 2012), para. 59.</p> <p><b>CRC Committee:</b> Noting with concern that in <b>Syria</b> there is limited availability of youth-friendly reproductive health services and that knowledge among adolescents about reproductive health, sexually transmitted diseases, including HIV/AIDS, and the health consequences of tobacco, alcohol and drugs consumption is inadequate. CRC/C/SYR/CO/3-4 (CRC, 2012), para. 65.</p> <p><b>CRC Committee:</b> Recommending that <b>Bulgaria</b> take all necessary measures to address the incidence of drug, alcohol, tobacco, and other substance use among children by, inter alia, providing children with accurate and objective information about toxic substance use, including tobacco use. CRC/C/BGR/CO/2 (CRC, 2008), para. 50.</p> <p><b>CRC Committee:</b> Recommending that <b>Panama</b> undertake steps to reduce the greater risk of HIV/AIDS among indigenous children, including by providing culturally sensitive sex education and information on reproductive health, reduce the greater risk of HIV/AIDS among teenagers by providing reproductive health services especially aimed at them and by expanding their access to information on prevention of sexually transmitted diseases, and that it direct programs at children with HIV/AIDS. CRC/C/PAN/CO/3-4 (CRC, 2011), para. 59.</p> <p><b>CRC Committee:</b> Expressing concern that indigenous children and children of Afro descendants in <b>Venezuela</b> do not receive sufficient information relevant to their needs. CRC/C/VEN/CO/2 (CRC, 2007), para. 41.</p> <p><b>CRC Committee:</b> Expressing concern that children in <b>Burkina Faso</b> still have a limited access to appropriate information which is mainly disseminated only in French, a language that most children do not understand. CRC/C/BFA/CO/3-4 (CRC, 2010), para. 36.</p>



**Table 4 (cont.)**

Human Rights Standards	Case Law
<p><b>ESC 11:</b> With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in cooperation with public or private organisations, to take appropriate measures designed inter alia: <b>(2)</b> to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health.</p>	<p><b>ECSR:</b> Holding that the situation in <b>Croatia</b> is not in conformity with Article 11§2 of the Charter, because Croatian schools do not provide comprehensive or adequate sexual and reproductive health education for children and young people. The Committee stated that governments that have signed the European Social Charter are obliged to provide scientifically-based and non-discriminatory sex education to young people that does not involve censoring, withholding or intentionally misrepresenting information such as on contraception. <i>International Centre for the Legal Protection of Human Rights (INTERIGHTS) v. Croatia</i> Complaint No. 45/2007, 30 March 2009.</p>

**Table 5: Children's Health and the Freedom from Abuse, Torture and Ill-Treatment**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Failure to criminalize corporal punishment against children in schools and homes.</li> <li>• Insufficient measures taken to protect children from domestic violence, abuse and neglect, including the absence of legislation and/or a national framework for protection.</li> <li>• Torture and ill-treatment of children in detention by police and security forces.</li> <li>• Sexual violence and abuse of children, particularly girls.</li> </ul>

**Table 5 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 19(1):</b> States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.</p>	<p><b>CRC Committee:</b> Recommending that states take practical steps, including enacting legislation, to prohibit corporal punishment. It should likewise encourage non-violent forms of discipline as alternatives to corporal punishment in the education system, and should conduct public information campaigns to explain its harmful effects. <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 38, <b>Djibouti</b> CRC/C/DJI/CO/2 (CRC, 2008) para. 36, <b>Georgia</b> CRC/C/GEO/CO/3 (CRC, 2008) para. 32, <b>Serbia</b> CRC/C/SRB/CO/1 (CRC, 2008) para. 47, <b>Panama</b> CRC/C/PAN/CO/3-4 (CRC, 2011) para. 46, <b>Syria</b> CRC/C/SYR/CO/3-4 (CRC, 2012), para. 53, <b>Italy</b> CRC/C/ITA/CO/3-4 (CRC, 2012), para. 34, <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011), para. 57, <b>Singapore</b> CRC/C/SGP/CO/2-3 (CRC, 2010), para. 39.</p> <p><b>CRC Committee:</b> Noting with great concern that children in <b>Burkina Faso</b> are commonly beaten, whipped, insulted and humiliated by their teachers. CRC/C/BFA/CO/3-4 (CRC, 2010), para. 40.</p> <p><b>CRC Committee:</b> Expressing concern that the rate of bullying at schools in the <b>Republic of Korea</b> has increased in occurrence and severity. CRC/C/KOR/CO/3-4 (CRC, 2012), para. 44.</p> <p><b>CRC Committee:</b> Expressing concern about high levels of domestic violence against children, and especially girls in <b>Algeria</b> CRC/C/DZA/CO/3-4 (CRC, 2012), para. 45; <b>Argentina</b> CRC/C/ARG/CO/3-4 (CRC, 2010), para. 53; <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010), para. 50; <b>Burundi</b> CRC/C/BDI/CO/2 (CRC, 2010), para. 41; and <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), para. 53.</p> <p><b>CRC Committee:</b> Expressing concern about the lack of child protection mechanisms against abuse in <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010), para. 50; <b>Italy</b> CRC/C/ITA/CO/3-4 (CRC, 2012), para. 43; and <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 45.</p> <p><b>CRC Committee:</b> Expressing concern that there is still no specific provision in domestic legislation in <b>Algeria</b> or <b>Burkina Faso</b> that criminalizes domestic violence. CRC/C/DZA/CO/3-4 (CRC, 2012), para. 45, CRC/C/BFA/CO/3-4 (CRC, 2010), para. 50.</p> <p><b>CRC Committee:</b> Regretting that there is no mandatory obligation for professionals working with children in <b>Singapore</b> to report abuse of children. CRC/C/SGP/CO/2-3 (CRC, 2010) para. 50.</p>
<p><b>CRC 37 (a):</b> No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment. Neither capital punishment nor life imprisonment without possibility of release shall be imposed for offences committed by persons below eighteen years of age.</p>	<p><b>CRC Committee:</b> Expressing deep concern that many children in <b>Syria</b> are reported to have died as a result of torture and mutilation they were subjected to while being detained in connection with the protests. It is also deeply concerned that children are still reported to be detained and at risk of torture. CRC/C/SYR/CO/3-4 (CRC, 2012), para. 50.</p> <p><b>CRC Committee:</b> Noting with deep regret the acknowledgment by <b>Egypt</b> in its report that violations of the right of the child to protection from torture and ill-treatment still occur. CRC/C/EGY/CO/3-4 (CRC, 2011), para. 122.</p> <p><b>CRC Committee:</b> Expressing serious concern at the lack of concrete measures taken by <b>Burkina Faso</b> on the conditions of detention of children in police stations and the methods used by law enforcement officials. CRC/C/BFA/CO/3-4 (CRC, 2010), para. 38.</p> <p><b>CRC Committee:</b> Expressing concern at allegations of torture and ill-treatment by police against children in <b>Argentina</b> CRC/C/ARG/CO/3-4 (CRC, 2010), para. 41; and against Roma children in the <b>Ukraine</b> CRC/C/15/ADD.191 (CRC, 2002), para. 36.</p>

**Table 5 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR (10):</b> The widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children.</p>	<p><b>CESCR:</b> Calling on <b>Brazil</b> to implement measures against child sexual abuse, especially the abuse of girls; to properly investigate instances of abuse and neglect of children within a child-sensitive inquiry; to provide support services to children in legal proceedings; and for the physical and psychological recovery and social reintegration of the victims of rape and other sexual abuse or violence. E/C.12/BRA/CO/2 (CESCR, 2009).</p> <p><b>CESCR:</b> Noting with concern that corporal punishment is lawful in <b>Ethiopia</b> E/C.12/ETH/CO/1-3 (CESCR, 2012), and not explicitly prohibited by law in <b>Belgium</b> E/C.12/BEL/CO/3 (CESCR, 2008), <b>Turkey</b> E/C.12/TUR/CO/1 (CESCR, 2011), and <b>United Kingdom of Great Britain and Northern Ireland</b> E/C.12/GBR/CO/5 (CESCR, 2009).</p> <p><b>CESCR:</b> Expressing concern at the high incidence of domestic violence against women and children in <b>India</b> E/C.12/IND/CO/5 (CESCR, 2008), <b>Kazakhstan</b> E/C.12/KAZ/CO/1 (CESCR, 2010), and <b>Latvia</b> E/C.12/LVA/CO/1 (CESCR, 2008).</p> <p><b>CESCR:</b> Expressing concern that domestic violence is not specifically defined as an offence in the Criminal Code of <b>Peru</b> E/C.12/PER/CO/2-4 (CESCR, 2012), or <b>Poland</b> E/C.12/POL/CO/5 (CESCR, 2009).</p>
<p><b>ICCPR (7):</b> The right to freedom from torture and cruel, inhuman, and degrading treatment.</p>	<p><b>HRC:</b> Urging <b>New Zealand</b> to further strengthen its efforts to combat child abuse by improving mechanisms for its early detection, encouraging reporting of suspected and actual abuse, and by ensuring that the relevant authorities take legal action against those involved in child abuse. CCPR/C/NZL/CO/5 HRC, 2009, para. 18.</p>
<p><b>CEDAW 2:</b> States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women</p>	<p><b>CEDAW General Recommendation 19:</b> Gender-based violence is a form of discrimination that seriously inhibits women's ability to enjoy rights and freedoms on a basis of equality with men. (11<sup>th</sup> Session, 1992).</p> <p><b>CEDAW Committee:</b> Calling on <b>Algeria</b> to strengthen the mechanisms and procedures for ensuring that refugee women and girls are not subjected to sexual and gender-based violence and abuse, and that victims/survivors have access to shelter, to medical and psychological services, and to law enforcement mechanisms and justice. CEDAW/C/DZA/CO/3-4 (CEDAW, 2012)</p> <p><b>CEDAW Committee:</b> Expressing concern for the situation of women and girls living in urban slums and informal settlements in <b>Kenya</b> and who are under threat of sexual violence and lack access to adequate sanitation facilities, which exacerbate their risks of being victims of sexual violence and impact negatively on their health. CEDAW/C/KEN/CO/7 (CEDAW, 2011).</p> <p><b>CEDAW Committee:</b> Calling on <b>Sri Lanka</b> to ensure that crisis centers and shelters where victims of domestic violence can find safe lodging and counseling are available and accessible throughout the country. E/C.12/LKA/CO/2-4 (CESCR, 2010).</p>

**Table 5 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CAT 2:</b> Each State Party shall take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under its jurisdiction.</p> <p><b>CAT 16(1):</b> Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article 1, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.</p>	<p><b>CAT Committee:</b> Calling on states to incorporate into domestic legislation a provision prohibiting the use of corporal punishment against children within the family and domestic violence against women. <b>Algeria</b> CAT/C/DZA/CO/3 (CAT, 2008), <b>Benin</b> CAT/C/BEN/CO/2 (CAT, 2008), <b>Chad</b> CAT/C/TCD/CO/1 (CAT, 2009), <b>Djibouti</b> CAT/C/DJI/CO/1 (CAT, 2011), <b>Ethiopia</b> CAT/C/ETH/CO/1 (CAT, 2011), <b>Zambia</b> CAT/C/ZMB/CO/2 (CAT, 2008), <b>Paraguay</b> CAT/C/PRY/CO/4-6 (CAT, 2011), <b>Slovenia</b> CAT/C/SVN/CO/3 (CAT, 2011), and <b>Ireland</b> CAT/C/IRL/CO/1 (CAT, 2011).</p> <p><b>CAT Committee:</b> Expressing concern that corporal punishment is lawful and frequently used in juvenile prisons in <b>Indonesia</b> CAT/C/IDN/CO/2 (CAT, 2008) and <b>Sri Lanka</b> CAT/C/LKA/CO/3-4 (CAT, 2011).</p> <p><b>CAT Committee:</b> Expressing concern about juvenile detention centres in <b>Kazakhstan</b>, where there are reports of incidents of self-mutilation by detainees. A/56/44(SUPP) (CAT, 2001).</p> <p><b>CAT Committee:</b> Urging <b>Cambodia</b> to take effective measures to prevent and combat sexual violence and abuse against women and children, including rape; establish and promote an effective mechanism for receiving complaints of sexual violence and investigate such complaints, providing victims with psychological and medical protection as well as access to redress, including compensation and rehabilitation, as appropriate. CAT/C/KHM/CO/2 (CAT, 2011).</p> <p><b>CAT Committee:</b> Expressing deep concern that hospitalized patients in <b>Burundi</b>, including children, who are unable to pay their medical expenses are detained in hospitals for several months until they are able to pay, and the conditions under which such patients are held, particularly fact that they are denied food and medical treatment. CAT/C/BDI/CO/1 (CAT, 2007).</p>

Human Rights Standards	Case Law
<p><b>ECHR 3:</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.</p>	<p><b>ECtHR:</b> Finding that the law in the <b>United Kingdom</b> that allowed for “reasonable punishment” of children, which was used as an effective defense for the caning of a supposedly “difficult” 9-year old boy by his step-father, failed to protect the child from torture, inhuman or degrading treatment or punishment in violation of Article 3. <i>A. v. United Kingdom</i>, 25599/94 (September 23, 1998). [**Following this and a series of other judgments and decisions, corporal punishment was banned in all United Kingdom schools.]</p> <p><b>ECtHR:</b> Concluding that the social service system in the <b>United Kingdom</b> that allowed for the appalling long-term neglect and emotional abuse of four very young children/babies by their parents, failed to protect children. The court held there was a violation of Articles 3 and 13 (right to an effective remedy). <i>Z and Others v. United Kingdom</i>, 29392/95 (May 10, 2001).</p> <p><b>ECtHR:</b> Finding that the beating of a 12-year old boy by police officers in <b>Turkey</b> to induce him to confess to stealing money from his employer (an accusation that was subsequently withdrawn) constituted a violation of Article 3; expressing concern at the impunity of the police officers and the absence of special protection for a minor. <i>Okkali v. Turkey</i>, 52067/99 (October 17, 2006).</p> <p><b>ECtHR:</b> Finding a violation of Article 3 where a 12-year-old boy was ill-treated by police officers while being held in police custody, after he refused to give his name in an identity check, leaving him with bruises on his thigh and near his right eye. The Court found that the boy had been subjected to inhuman and degrading treatment and that there had been no effective punishment of the police officer responsible, in further violation of Article 3. <i>Ci erhun Öner v. Turkey</i> (no. 2), 2858/07 (November 23, 2010).</p>

## Table 5 (cont.)

### Other Interpretations

**Advisory Opinion of the IACtHR:** States parties to the American Convention on Human Rights “are under the obligation ... to adopt all positive measures required to ensure protection of children against mistreatment, whether in their relations with public authorities, or in relations among individuals or with non-governmental entities.” OC-17/2002 (28 August 2002), paras. 87 and 91.

**CRC General Comment 8 - The right of the child to protection from corporal punishment and other cruel or degrading forms of punishment.** CRC/C/GC/8 (2006).

**SR Torture:** Recommending that **Kazakhstan** ensure that corporal punishment is explicitly criminalized in all parts of the country. A/HRC/7/3/Add.7 (SR Torture, 2008).

**SR Torture:** Recommending that the Government of **Nigeria** take decisive steps to abolish all forms of corporal punishment, including shariabased punishments. A/HRC/7/3/Add.4 (2007).

**SR Torture:** Noting with concern that in prisons in **Equatorial Guinea**, as well as in police and gendarmerie custody, women and children are not separated from male adults and are therefore extremely vulnerable to sexual violence and other forms of abuse by guards as well as by co-prisoners. A/HRC/13/39/Add.4 (2010).

**SR Violence Against Women:** Recommending legal provisions to prevent and combat violence in the family in **Algeria** A/HRC/7/6/Add.2 (2008) and the **Republic of Moldova** A/HRC/11/6/Add.4 (2009).

**SR Torture:** Expressing serious concern about the greater vulnerability of minors to ill-treatment in police stations and consistent allegations of beatings after arrest, as well as the seemingly excessive use of force and collective punishment after riots and rebellions in detention facilities for minors in **Uruguay**. A/HRC/13/39/ADD.2 (SR Torture, 2009).

**United Nations Study on Violence Against Children**, A/61/299 (2006).

## Table 6: Children's Health and the Rights of Children with Disabilities

### Examples of Human Rights Violations

- Limitations in access to education and health care services for children with disabilities.
- Lack of a comprehensive government policy for children with disabilities that considers their overall development needs, including the right to health.
- Discrimination and stigmatization of children with disabilities.
- Limited availability of special education teachers, or lack of training of mainstream teachers.

**Table 6 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 23(1):</b> States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.</p> <p><b>(2):</b> States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.</p> <p><b>(3):</b> Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.</p>	<p><b>CESCR General Comment 14(22):</b> Children with disabilities should be given the opportunity to enjoy a fulfilling and decent life and to participate within their community.</p> <p><b>CRC Committee:</b> Recommending that <b>Bhutan</b> adopt an inclusive education strategy and elaborate a plan of action in order to increase the school attendance of children with special needs and focus on day-care services for these children in order to prevent their institutionalization; and ensure that all children with special needs receive the appropriate care. CRC/C/SR.1369 (CRC, 2008), para. 51.</p> <p><b>CRC Committee:</b> Regretting the lack of a comprehensive government policy for children with disabilities in the <b>United Kingdom</b> CRC/C/GBR/CO/4 (CRC, 2008), para. 52; <b>Georgia</b> CRC/C/GEO/CO/3 (CRC, 2008), para. 42; and <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), para. 55.</p> <p><b>CRC Committee:</b> Expressing concern about barriers to and the quality of education for children with disabilities in <b>Algeria</b> CRC/C/DZA/CO/3-4 (CRC, 2012), para. 55; <b>Argentina</b> CRC/C/ARG/CO/3-4 (CRC, 2010), para. 50; <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), para. 43; <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010), para. 52; <b>Burundi</b>. CRC/C/BDI/CO/2 (CRC, 2010) para. 50; <b>Korea</b> CRC/C/KOR/CO/3-4 (CRC, 2012), para. 51; <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 47; <b>Serbia</b> CRC/C/SRB/CO/1 (CRC, 2008), para. 48.</p> <p><b>CRC Committee:</b> Expressing concern about barriers to and the quality of health care for children with disabilities in <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), para. 43; and <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 47.</p> <p><b>CRC Committee:</b> Concerned with the non-universal health care insurance for children with disabilities in <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011), para. 60; and <b>Argentina</b> CRC/C/ARG/CO/3-4 (CRC, 2010), para. 50.</p> <p><b>CRC Committee:</b> Remaining concerned at the reported treatment of children with disabilities in some social care institutions in <b>Serbia</b>, in which severe and long-term forms of restraint and seclusion have reportedly taken place, and it is concerned that such practices could amount to ill-treatment or even torture. CRC/C/SRB/CO/1 (CRC, 2008), para. 35.</p>

**Other Interpretations**

Convention on the Rights of Persons with Disabilities.

CRC General Comment 9: The Rights of Children with Disabilities. CRC/C/GC/9 (2006).



**Table 7: Children's Health and the Right to the Highest Attainable Standard of Health**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• High levels of infant, under-five and maternal mortality rates due to limited access to health services.</li> <li>• The low level of vaccination rates, due in part to the lack of health workers.</li> <li>• Wide disparity in the provision of health services, particularly in rural areas.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(1):</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p> <p><b>(2):</b> States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:</p> <p><b>(a)</b> To diminish infant and child mortality;</p> <p><b>(b)</b> To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;</p> <p><b>(c)</b> To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution . . .</p>	<p><b>CRC General Comment 12(101):</b> States parties need to introduce legislation or regulations to ensure that children have access to confidential medical counseling and advice without parental consent, irrespective of the child's age, where this is needed for the child's safety or well-being. Children may need such access, for example, where they are experiencing violence or abuse at home, or in need of reproductive health education or services, or in case of conflicts between parents and the child over access to health services. The right to counseling and advice is distinct from the right to give medical consent and should not be subject to any age limit.</p> <p><b>CRC Committee:</b> Expressing concern that maternal, neonatal and under-five mortality rates, remain at very high levels in <b>Algeria</b>, CRC/C/DZA/CO/3-4 (CRC, 2012), para. 57; <b>Argentina</b> CRC/C/ARG/CO/3-4 (CRC, 2010), para. 57; <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 49; <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010), para. 54; and noting the disparities in maternal mortality in <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011); <b>Italy</b> CRC/C/ITA/CO/3-4 (CRC, 2012), para. 47.</p> <p><b>CRC Committee:</b> Noting with concern the legislative provisions in <b>Georgia</b> and <b>Bulgaria</b> which stipulate that a child under the age of 16 who wishes to see a doctor must be accompanied by a parent; and urging the State parties to take legislative measures to ensure to all children under the age of 16 free and confidential access to medical counsel and assistance with or without parental consent. CRC/C/SR.1342 (CRC, 2008), paras. 47, CRC/C/BGR/CO/2 (CRC, 2008) para. 47.</p> <p><b>CRC Committee:</b> Expressing concern at high levels of malnutrition of children in <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 49; <b>Algeria</b> CRC/C/DZA/CO/3-4 (CRC, 2012), para. 57; <b>Burundi</b> CRC/C/BDI/CO/2 (CRC, 2010), para. 52; <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010), para. 54; <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 52; <b>Panama</b> CRC/C/PAN/CO/3-4 (CRC, 2011), para. 54.</p> <p><b>CRC Committee:</b> Noting with concern that many children living in remote or rural areas have limited access to medical care resulting in considerable variations in children's health status in <b>Georgia</b> CRC/C/GEO/CO/3 (CRC, 2008), para. 44; <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), para. 45; <b>Serbia</b> CRC/C/SRB/CO/1 (CRC, 2008), para. 50; <b>Syria</b> CRC/C/SYR/CO/3-4 (CRC, 2012), para. 63; <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011), para. 62; <b>Panama</b> CRC/C/PAN/CO/3-4 (CRC, 2011), para. 54; <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), para. 57; in <b>Korea</b>. CRC/C/KOR/CO/3-4 (CRC, 2012), para. 53 and <b>Burundi</b> CRC/C/BDI/CO/2 (CRC, 2010), para. 52.</p> <p><b>CRC Committee:</b> Noting discriminatory practices in health provision in <b>Bulgaria</b> CRC/C/SR.1318 (CRC, 2008), para. 45 and in <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), para. 57.</p>



**Table 7 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1)</b> : The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<b>CESCR</b> : Expressing concern about the high levels of maternal and infant under-five mortality in <b>Madagascar</b> E/C.12/MDG/CO/2 (CESCR, 2009); <b>Nepal</b> E/C.12/NPL/CO/2 (CESCR, 2008) and infant mortality in the <b>Republic of Moldova</b> E/C.12/MDA/CO/2 (CESCR, 2011).

Human Rights Standards	Case Law
<p><b>African Children's Charter 14(1)</b>: Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health.</p> <p><b>(2)</b> State Parties to the present Charter shall undertake to pursue the full implementation of this right:</p> <p><b>(b)</b> to ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;</p> <p><b>(g)</b> to integrate basic health service programmes in national development plans.</p>	<p><b>ACHPR Committee</b>: Finding that <b>Kenya</b> violated the right to health of children of Nubian descent, stating that "[t]here is de facto inequality in their access to available health care resources, and this can be attributed in practice to their lack of confirmed status as nationals of the Republic of Kenya. Their communities have been provided with fewer facilities and a disproportionately lower share of available resources as their claims to permanence in the country have resulted in health care services in the communities in which they live being systematically overlooked over an extended period of time." <i>IHRDA and Open Society Justice Initiative (OSJI) (on behalf of children of Nubian descent in Kenya) v. Kenya</i>. 002/09 March 22, 2011.</p>

**Table 8: Children's Health and the Right to Sexual and Reproductive Health and Education, Including on HIV**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Insufficient efforts to provide adolescents to appropriate reproductive health services, including reproductive health education in school.</li> <li>• High rates of unplanned pregnancies among adolescents and the correspondingly high rates of abortion among adolescents in such situations.</li> <li>• High rates of sexually transmitted diseases including HIV, due in part to the lack of awareness of prevention methods and low use of contraceptives.</li> <li>• Limited efforts to combat traditional beliefs that intercourse with a virgin cures HIV infection, which increases the vulnerability of women and, especially, young girls to infection.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(1):</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p> <p><b>(2):</b> States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures: (f) To develop preventive health care, guidance for parents and family planning education and services.</p>	<p><b>CRC General Comment 3:</b> Consistent with the obligations of States parties in relation to the rights to health and information, children should have the right to access adequate information related to HIV/AIDS prevention and care, through formal channels (e.g. through educational opportunities and child-targeted media) as well as informal channels (e.g. those targeting street children, institutionalized children or children living in difficult circumstances). States parties are reminded that children require relevant, appropriate and timely information which recognizes the differences in levels of understanding among them, is tailored appropriately to age level and capacity and enables them to deal positively and responsibly with their sexuality in order to protect themselves from HIV infection. CRC/GC/2003/3.</p> <p><b>CRC Committee:</b> Expressing concern at the high rates of teenage pregnancies and recommending increased efforts for adolescent reproductive health services in the <b>United Kingdom</b> CRC/C/GBR/CO/4 (CRC, 2008), paras. 60, 61; <b>Serbia</b> CRC/C/SRB/CO/1 (CRC, 2008), paras. 54, 55; <b>Korea</b> CRC/C/KOR/CO/3-4 (CRC, 2012), para. 58; <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), paras. 51, 52.</p> <p><b>CRC Committee:</b> Recommending increased information and education on adolescent reproductive health in <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 55; <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), para. 58; <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), para. 6; <b>Syria</b> CRC/C/SYR/CO/3-4 (CRC, 2012), para. 65.</p> <p><b>CRC Committee:</b> Noting with significant concern that the majority of married girls aged 15 – 17 in <b>Egypt</b> never used family planning methods. CRC/C/EGY/CO/3-4 (CRC, 2011), para. 64.</p> <p><b>CRC Committee:</b> Recommending strengthened preventive efforts on HIV/AIDS through awareness, education and increased programs in <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 59; <b>Panama</b> CRC/C/PAN/CO/3-4 (CRC, 2011), para. 59; <b>Syria</b> CRC/C/SYR/CO/3-4 (CRC, 2012), para. 65.</p> <p><b>CRC Committee:</b> Noting with concern that in <b>Burkina Faso</b>, only 10% of HIV infected children receive medical care because of the lack of available health structures to care for them and the reluctance of families to have their children tested. CRC/C/BFA/CO/3-4 (CRC, 2010), para. 60.</p>

**Table 8 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 10:</b> States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education and in particular to ensure, on a basis of equality of men and women: <b>(h)</b> Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning</p>	<p><b>CEDAW General Recommendation 24 (18):</b> The issues of HIV/AIDS and other sexually transmitted disease are central to the rights of women and adolescent girls to sexual health. Adolescent girls and women in many countries lack adequate access to information and services necessary to ensure sexual health. (20<sup>th</sup> Session, 1999).</p> <p><b>CEDAW Committee:</b> Recommending that sex education be widely promoted and targeted at adolescent girls and boys, with special attention to the prevention of early pregnancy and the control of sexually transmitted infections in <b>Egypt</b> CEDAW/C/EGY/CO/7 (CEDAW, 2010); <b>Uzbekistan</b> CEDAW/C/UZB/CO/4 (CEDAW, 2010); <b>Lao People's Democratic Republic</b> CEDAW/C/LAO/CO/7 (CEDAW, 2007); and <b>United Republic of Tanzania</b> CEDAW/C/TZA/CO/6 (CEDAW, 2009).</p> <p><b>CEDAW Committee:</b> Expressing concern about the high rate of teenage pregnancy in <b>Paraguay</b> and <b>Uganda</b>, which affects the continuation and completion of education for girls. CEDAW/C/PRY/CO/6 (CEDAW, 2011) CEDAW/C/UGA/CO/7 (CEDAW, 2010).</p> <p><b>CEDAW Committee:</b> Noting that additional efforts are needed to raise awareness, especially among youth, about the risks and effects of HIV, AIDS and other sexually transmitted infections <b>Zambia</b>. CEDAW/C/ZMB/CO/5-6 (CEDAW, 2011).</p> <p><b>CEDAW Committee:</b> Recommending that <b>Ethiopia</b> provide free antiretroviral treatment for pregnant women living with HIV/AIDS to prevent mother-to-child transmission; and conduct awareness-raising activities to de stigmatize orphans and vulnerable children affected by HIV/AIDS and strengthen the material and psychological support provided to them. CEDAW/C/ETH/CO/6-7 (CEDAW, 2011).</p>
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR:</b> Noting with concern that in <b>Kazakhstan</b>, sexual and reproductive health services, particularly for teenagers, are not available and there is a lack of comprehensive sexual and reproductive health education programs for adolescents in the national school curricula that provide them with objective information in accordance with medical and education standards. E/C.12/KAZ/CO/1 (2010).</p> <p><b>CESCR:</b> Recommending that <b>Bolivia</b> openly address the subjects of sex education and family planning in school curricula in order to help prevent early pregnancies and the spread of sexually-transmitted diseases. E/C.12/BOL/CO/2 (CESCR, 2008)</p>

Human Rights Standards	Case Law
<p><b>ESC 11:</b> With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed inter alia: <b>(2)</b> to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health.</p>	<p><b>ECSR:</b> Finding a violation of Article 11(2) in light of the non-discrimination clause where sexual education materials in <b>Croatia</b> was scientifically inaccurate, gender stereotyped or outright discriminatory on grounds of sexuality and/or family status; stating that in the positive obligation to provide sexual and reproductive health extends to ensuring that educational materials do not reinforce demeaning stereotypes and perpetuate forms of prejudice which contribute to the social exclusion, embedded discrimination and denial of human dignity often experienced by historically marginalized groups such as persons of non-heterosexual orientation.</p> <p>The reproduction of such state-sanctioned material in educational materials not alone has a discriminatory and demeaning impact upon persons of non-heterosexual orientation throughout Croatian society, but also presents a distorted picture of human sexuality to the children exposed to this material. By permitting sexual and reproductive health education to become a tool for reinforcing demeaning stereotypes, the authorities have failed to discharge their positive obligation not to discriminate in the provision of such education, and have also failed to take steps to ensure the provision of objective and non-exclusionary health education. <i>International Centre for the Legal Protection of Human Rights (INTERIGHTS) v. Croatia</i>, Complaint No. 45/2007, 30 March 2009.</p>

## Table 8 (cont.)

### Other Interpretations

**SR Health:** Recommending that the **Syrian Arab Republic** develop and implement a consistent, nation-wide sexual and reproductive health education curricula, to be delivered through late primary and early secondary schools. A/HRC/17/25/Add.3 (2011).

**International Guidelines on HIV/AIDS and Human Rights 8 (g)** States should ensure the access of children and adolescents to adequate health information and education ... [and] **(h)** ... confidential sexual and reproductive health services, including HIV information, counseling, testing, and prevention measures.

## Table 9: Children's Health and the Right to Education

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Legislation requiring payment for primary education, or otherwise making primary education not accessible in an equitable manner for all children.</li> <li>• High dropout rates, particularly among children belonging to vulnerable groups, including children from rural areas; children living in economic hardship and deprivation; Roma children and children from other minority groups; refugee and internally displaced children.</li> <li>• Poor conditions of school buildings and facilities, which pose health and safety risks for children.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 28 (1):</b> States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:</p> <p><b>(a)</b> Make primary education compulsory and available free to all;</p> <p><b>(b)</b> Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;</p> <p><b>(c)</b> Make higher education accessible to all on the basis of capacity by every appropriate means;</p> <p><b>(d)</b> Make educational and vocational information and guidance available and accessible to all children;</p> <p><b>(e)</b> Take measures to encourage regular attendance at schools and the reduction of drop-out rates.</p>	<p><b>CRC General Comment 1 (9):</b> Education must also be aimed at ensuring that ... no child leaves school without being equipped to face the challenges that he or she can expect to be confronted with in life. Basic skills should include ... the ability to make well-balanced decisions, to resolve conflicts in a nonviolent manner, and to develop a healthy lifestyle [and] good social relationships. CRC/GC/2001/1 (April 17, 2001).</p> <p><b>CRC Committee:</b> Expressing concern at the quality of education in <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 61; <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), paras. 67, 69; and <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011), para. 74.</p> <p><b>CRC Committee:</b> Noting the lack of non-formal, vocational education options for <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 61; <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), paras. 58 (b)(h); <b>Panama</b> CRC/C/PAN/CO/3-4 (CRC, 2011), para. 62 (a).</p> <p><b>CRC Committee:</b> Expressing concern at the dropout levels in <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), paras. 58 (b)(h); <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011), para. 74; <b>Italy</b> CRC/C/ITA/CO/3-4 (CRC, 2012), para. 59; and <b>Serbia</b> CRC/C/SRB/CO/1 (CRC, 2008), para. 60(d); <b>Syria</b> CRC/C/SYR/CO/3-4 (CRC, 2012), para. 71(a); and <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 57.</p> <p><b>CRC Committee:</b> Expressing concern at the rate and quality of education for indigenous/minority children in <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), paras. 67, 69; <b>Italy</b> CRC/C/ITA/CO/3-4 (CRC, 2012), para. 59; and <b>Serbia</b> CRC/C/SRB/CO/1 (CRC, 2008), para. 60(d).</p> <p><b>CRC Committee:</b> Calling attention to the highly competitive nature of the education system in <b>Singapore</b>, which may impose undue stress and prevent children from developing to their full potential. CRC/C/SGP/CO/2-3 (CRC, 2010), para. 58.</p>

**Table 9 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 13:</b> Everyone has the right to education. Primary education should be compulsory and free to all.</p> <p><b>ICESCR 14:</b> Those States where compulsory, free primary education is not available to all should work out a plan to provide such education.</p>	<p><b>CESCR:</b> Expressing concern about the high dropout and repetition rates in <b>Peru</b> E/C.12/PER/CO/2-4 (CESCR, 2012); and <b>Germany</b> E/C.12/DEU/CO/5 (CESCR, 2011).</p> <p><b>CESCR:</b> Recommending increased efforts to ensure effective access to education by Roma children and other vulnerable groups in <b>Italy</b> CERD/C/ITA/CO/16-18 (CERD, 2012); <b>Slovakia</b> E/C.12/SVK/CO/2 (CESCR, 2012).</p> <p><b>CESCR:</b> Expressing concern to <b>Israel</b> that Palestinian children living in the Occupied Palestinian Territory are not able to enjoy their right to education, as a consequence of restrictions on their movement, regular harassment by settlers of children and teachers on their way to and from school, attacks on educational facilities, and sub-standard school infrastructure. E/C.12/ISR/CO/3 (CESCR, 2011).</p>
<p><b>ICERD 5:</b> States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, color, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights:</p> <p><b>(e)(v)</b> The right to education and training.</p>	<p><b>CERD:</b> Expressing concern that, in some regions of <b>Spain</b>, there are “ghetto” schools for migrant and Gypsy children. CERD/C/ESP/CO/18-20 (CERD, 2011).</p> <p><b>CERD:</b> Recommending that <b>Norway</b> find appropriate solutions for integrating children from Roma and Romani communities into the educational system to ensure that they benefit fully from all levels of the system, taking into account the community’s lifestyle and including an enhanced teaching provision in their language. CERD/C/NOR/CO/19-20 (CERD, 2011).</p> <p><b>CERD:</b> Recommending that <b>Denmark</b> provide a general educational policy to cover all groups and take appropriate measures to assess whether people of other ethnic groups require mother-tongue teaching. CERD/C/DNK/CO/18-19 (CERD, 2010).</p> <p><b>CERD:</b> Recommending that <b>Vietnam</b> take vigorous measures to ensure equal enjoyment of the right to education by, inter alia, increasing the financial assistance provided for students from economically disadvantaged families in all communities, and improving the quality of teaching and the curriculum. Furthermore, the State party should: increase the provision of bilingual education programs for ethnic minority children and of training in local languages for Kinh teachers in ethnic minority areas; recruit more ethnic minority teachers; allow ethnic minority languages to be taught and used as a medium of instruction in schools; and support education programs on the culture of ethnic minority groups. CERD/C/VNM/CO/10-14 (CERD, 2012).</p>
<p><b>CEDAW 12:</b> State Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure to them equal rights with men in the field of education.</p>	<p><b>CEDAW Committee:</b> Recommending measures to ensure equal access to education and ensure retention of girls in school in <b>Turkey</b> CEDAW/C/TUR/CO/6 (CEDAW, 2010) and <b>Mauritius</b> CEDAW/C/MUS/CO/6-7 (CEDAW, 2011).</p> <p><b>CEDAW Committee:</b> Recommending that <b>Montenegro</b> adopt temporary special measures to increase enrolment and completion rates of Roma, Ashkali and Egyptian girls and boys. CEDAW/C/MNE/CO/1 (CEDAW, 2011).</p>

**Other Interpretations**

**SR Education:** encouraging **Mexico** to strengthen the services for families who migrate within the country, known as day laborers (jornaleros). In order to provide them with opportunities to obtain quality education, the school terms should be brought into line with the farming seasons, and the coverage should be expanded to include secondary education; it is also essential to harmonize the education service with the work obligations of working parents and young people. A/HRC/14/25/ADD.4 (SR Education, 2010).

**SR Education:** finding that **Paraguay** urgently needs resources to solve infrastructure problems and or drinking water, school meals, culturally diverse teaching materials, teacher training and affirmative measures of all kinds to ensure that the poorest members of the community can get into educational establishments and stay there (the university gives certain indigenous people immediate access but does not meet their needs). A/HRC/14/25/ADD.2 (SR Education, 2010).

**Table 10: Children's Health and Freedom from Economic or Sexual Exploitation**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Recruitment of children in domestic services, agriculture, and mining.</li> <li>• The minimum age of employment is lower than the age of compulsory schooling, or lower than international standards.</li> <li>• High incidence of child labour and sex trafficking, with a harmful impact on the education and health of children.</li> <li>• Limited action to combat sexual exploitation and abuse of children, including rare prosecution of traffickers.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 32(1):</b> States Parties recognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development.</p> <p><b>(2):</b> States Parties shall take legislative, administrative, social and educational measures to ensure the implementation of the present article. To this end, and having regard to the relevant provisions of other international instruments, States Parties shall in particular:</p> <p><b>(a)</b> Provide for a minimum age or minimum ages for admission to employment;</p> <p><b>(b)</b> Provide for appropriate regulation of the hours and conditions of employment;</p> <p><b>(c)</b> Provide for appropriate penalties or other sanctions to ensure the effective enforcement of the present article.</p>	<p><b>CRC Committee:</b> Calling on <b>Bulgaria</b> to introduce monitoring mechanisms to ensure the enforcement of labor laws and protect children from economic exploitation. CRC/C/BGR/CO/2 (CRC, 2008), para. 60.</p> <p><b>CRC Committee:</b> Expressing concern over the high incidence of child labor in <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008), para. 66; <b>Syria</b> CRC/C/SYR/CO/3-4 (CRC, 2012), para. 76; <b>Madagascar</b> CRC/C/MDG/CO/3-4 (CRC, 2012), para. 59; <b>Costa Rica</b> CRC/C/CRI/CO/4 (CRC, 2011), para. 73; <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011), para. 78; and <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010), para. 68.</p> <p><b>CRC Committee:</b> Expressing concern that in <b>Singapore</b>, the minimum age of employment is lower than the age of compulsory schooling. CRC/C/SGP/CO/2-3 (CRC, 2010), para. 62.</p>
<p><b>CRC 34:</b> States Parties undertake to protect the child from all forms of sexual exploitation and sexual abuse. For these purposes, States Parties shall in particular take all appropriate national, bilateral and multilateral measures to prevent:</p> <p><b>(a)</b> The inducement or coercion of a child to engage in any unlawful sexual activity;</p> <p><b>(b)</b> The exploitative use of children in prostitution or other unlawful sexual practices;</p> <p><b>(c)</b> The exploitative use of children in pornographic performances and materials.</p>	<p><b>CRC Committee:</b> Expressing concern on trafficking and sexual exploitation of children in <b>Austria</b>. CRC/C/OPSC/AUT/1, CRC 2009, para. 16; <b>Burkina Faso</b> CRC/C/BFA/CO/3-4 (CRC, 2010), para. 72; and the lack of physical and psychosocial rehabilitation services for victims in <b>Egypt</b> CRC/C/EGY/CO/3-4 (CRC, 2011), para. 82. <b>CRC Committee:</b> Recommending increased efforts to prevent and combat sexual exploitation, prostitution and child abuse in <b>Bulgaria</b> CRC/C/BGR/CO/2 (CRC, 2008), para. 64 and <b>Bhutan</b> CRC/C/SR.1369 (CRC, 2008).</p> <p><b>CRC Committee:</b> Recommending that increase protection provided to sexually exploited and trafficked children, who should be treated as victims and not criminalized. <b>Serbia</b> CRC/C/SRB/CO/1 (CRC, 2008), para. 72.</p> <p><b>CRC Committee:</b> Expressing serious concern at the lack of available <b>CRC Committee:</b> noting with concern that <b>Singapore</b> has taken limited action to combat sexual exploitation and abuse of children, including child sex tourism. CRC/C/SGP/CO/2-3 (CRC, 2010), para. 64.</p>



**Table 10 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 10(3):</b> Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. Children and young persons should be protected from economic and social exploitation. Their employment in work harmful to their morals or health or dangerous to life or likely to hamper their normal development should be punishable by law. States should also set age limits below which the paid employment of child labor should be prohibited and punishable by law.</p>	<p><b>CESCR:</b> Noting with concern the prevalence of child labor, and that many are engaged in the worst forms of child labor in <b>Ethiopia</b> E/C.12/ETH/CO/1-3 (CESCR, 2012); <b>India</b> E/C.12/IND/CO/5 (CESCR, 2008); <b>Nepal</b> E/C.12/NPL/CO/2 (CESCR, 2008); <b>Paraguay</b> E/C.12/PRY/CO/3 (CESCR, 2008); <b>Peru</b> E/C.12/PER/CO/2-4 (CESCR, 2012); <b>Philippines</b> E/C.12/PHL/CO/4 (CESCR, 2008); <b>Republic of Moldova</b> E/C.12/MDA/CO/2 (CESCR, 2011); <b>Sri Lanka</b> E/C.12/LKA/CO/2-4 (CESCR, 2010); and <b>Ukraine</b> E/C.12/UKR/CO/5 (CESCR, 2008).</p> <p><b>CESCR:</b> Expressing deep concern that children work in conditions of bonded labor in <b>India</b> E/C.12/IND/CO/5 (CESCR, 2008), <b>Nepal</b> E/C.12/NPL/CO/2 (CESCR, 2008), and <b>Cambodia</b> E/C.12/KHM/CO/1 (CESCR, 2009).</p> <p><b>CESCR:</b> Noting with concern that the minimum age for admission to employment is too low in <b>Cameroon</b> and E/C.12/CMR/CO/2-3 (CESCR, 2012); <b>Peru</b> E/C.12/PER/CO/2-4 (CESCR, 2012); and <b>Turkey</b> E/C.12/TUR/CO/1 (CESCR, 2011)</p> <p><b>CESCR:</b> Calling on States to intensify the efforts to combat trafficking in human beings, especially women and children, for purposes of sexual exploitation and forced labor. <b>Cambodia</b> E/C.12/KHM/CO/1 (CESCR, 2009); <b>Dominican Republic</b> E/C.12/DOM/CO/3 (CESCR, 2010); and <b>Benin</b> E/C.12/BEN/CO/2 (CESCR, 2008).</p> <p><b>CESCR:</b> Recommending close monitoring of the number of women and children trafficked to, from and through territory each year in <b>Costa Rica</b> E/C.12/CRI/CO/4 (CESCR, 2008); <b>Hungary</b> E/C.12/HUN/CO/3 (CESCR, 2008); <b>Former Yugoslav Republic of Macedonia</b> E/C.12/MKD/CO/1 (CESCR, 2008).</p> <p><b>CESCR:</b> Noting that in <b>India</b>, trafficking in persons remains a serious problem; women and children belonging to scheduled castes and scheduled tribes make up a large proportion of victims of trafficking and sexual exploitation; victims of trafficking and sexual exploitation, rather than being afforded protection and rehabilitation, are prosecuted under the Immoral Trafficking Prevention Act (ITPA); and that there is no legislation that specifically criminalizes trafficking in persons. E/C.12/IND/CO/5 (CESCR, 2008).</p> <p><b>CESCR:</b> Noting with concern that in <b>Sri Lanka</b> thousands of children remain sexually abused and exploited including in child sex tourism; perpetrators of child sexual exploitation and abuse, including child traffickers are rarely prosecuted, while child victims may still be excluded from protection of the law and placed on remand for conducting prostitution. E/C.12/LKA/CO/2-4 (CESCR, 2010).</p>
<p><b>CEDAW 11:</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of employment in order to ensure, on a basis of equality of men and women, the same rights, in particular:</p> <p><b>(f)</b> The right to protection of health and to safety in working conditions.</p>	<p><b>CEDAW Committee:</b> Expressing concern at the persistence of child labor in <b>Guatemala</b>. CEDAW/C/GUA/CO/7 (CEDAW, 2009).</p> <p><b>CEDAW Committee:</b> Recommending that <b>El Salvador</b> strengthen efforts to eradicate child labor and support education as a means of empowering girls and boys, so as to ensure that there is a clear understanding of and effective compliance with the minimum working age throughout the State party. CEDAW/C/SLV/CO/7 (CEDAW, 2008).</p>



**Table 10 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 6:</b> States Parties shall take all appropriate measures, including legislation, to suppress all forms of traffic in women and exploitation of prostitution of women.</p>	<p><b>CEDAW Committee:</b> Calling on State Parties to intensify their efforts to combat all forms of trafficking in <b>Bhutan</b> CEDAW/C/BTN/CO/7 (CEDAW, 2009), <b>Tunisia</b> CEDAW/C/TUN/CO/6 (CEDAW, 2010), <b>Niger</b> CEDAW/C/NER/CO/2 (CEDAW, 2007), <b>Vietnam</b> CEDAW/C/VNM/CO/6 (CEDAW, 2007), <b>Tajikistan</b> CEDAW/C/TJK/CO/3 (CEDAW, 2007); <b>Belarus</b> CEDAW/C/BLR/CO/7 (CEDAW, 2011); and <b>Cape Verde</b> CEDAW/C/CPV/CO/6 (CEDAW, 2006).</p> <p><b>CEDAW Committee:</b> Expressing concern at the proliferation of sex tourism in <b>Mauritius</b>, essentially generating sexual exploitation of women and girls and augmenting the vulnerability of sex workers. CEDAW/C/MUS/CO/6-7 (CEDAW, 2011).</p> <p><b>CEDAW Committee:</b> Expressing concern about the low number of prosecutions and the lenient sentences imposed on traffickers in <b>Montenegro</b>; the limited capacity of the competent authorities to identify (potential) victims of trafficking, including women and girls from vulnerable groups; and the lack of victim protection and compensation. CEDAW/C/MNE/CO/1 (CEDAW, 2011).</p> <p><b>CEDAW Committee:</b> Recommending that <b>Chad</b> amend the Criminal Code so as to include trafficking in persons as an offence, and to consider adopting a comprehensive law against trafficking in persons, in line with the Palermo Protocol, in order to fully implement article 6 of the Convention, and to ensure that perpetrators are prosecuted and punished and victims adequately protected and assisted. CEDAW/C/TCD/CO/1-4 (CEDAW, 2011).</p>

Human Rights Standards	Case Law
<p><b>ECHR 4(1):</b> No one shall be held in slavery or servitude.</p> <p><b>(2):</b> No one shall be required to perform forced or compulsory labor.</p>	<p><b>ECtHR:</b> Holding that <b>France's</b> criminal code did not practically and effectively protect 15-year old Siliadin from slavery and servitude in violation of Article 4 of the ECHR. Siliadin, a 15-year old girl of Togolese origin, arrived in France with Mrs. D, a French national of Togolese origin, on a tourist visa. It had been agreed that Siliadin would work at Mrs. D's home until the cost of her airfare had been reimbursed and that Mrs. D would enroll her in school and take care of her immigration matters. Instead, Mr. and Mrs. D. took Siliadin's passport and forced her to work as an unpaid housemaid. She was later "lent" to Mr. and Mrs. B, who decided to "keep her" as an unpaid housemaid and child caretaker, working 15 hour days, seven days a week. She was not paid, not sent to school and her immigration matters were never handled. The Court found that France had violated Article 4 of the ECHR by not actively protecting its citizens from economic exploitation. <i>Siliadin v. France</i>, Judgement, merits and just satisfaction, 73316/01 (October 27, 2005).</p>

## Table 10 (cont.)

### Other Interpretations

**The Optional Protocol on the Sale of Children, Child Prostitution and Child Pornography (OPSC).** The OPSC criminalizes specific acts relating to the sale of children, child prostitution and child pornography, including attempt and complicity. It lays down minimum standards for protecting child victims in criminal justice processes and recognizes the right of victims to seek compensation.

**SR on the Sale of Children, Child Prostitution and Child Pornography (SR Sale of Children):** regarding the situation of Roma children, authorities in **Greece** are called upon to take specific measures to improve living conditions and possibilities for development of Roma communities to give Roma children alternatives other than work on streets or prostitution, as survival strategies for them and their families. E/CN.4/2006/67/Add.3 (SR Sale of Children, 2006).

**SR Sale of Children:** Recommending to **Greece** that specialized staff with adequate expertise to work with foreign unaccompanied minors, street children, and victims of trafficking is needed to ensure child's physical and psychological health, protection against exploitation and access to educational and vocational skills and opportunity. E/CN.4/2006/67/Add.3 (SR Sale of Children, 2006).

**SR Sale of Children:** Calling on the government of the **United Arab Emirates** to urgently regularize the situation of the bidoon children with a view to ensuring that they have access to health and education and thus decreasing their vulnerability to sexual exploitation. A/HRC/16/57/Add.2 (SR Sale of Children, 2010).

**SR on Contemporary Forms of Slavery, Including its Causes and Consequences:** Recommending that the government of **Romania** a) Develop additional programmes to support the implementation of the legislation relevant to the worst forms of child labor and other exploitative slave-like situations, emphasizing the role of individual state agencies and providing them with the necessary funding; and (b) Take further appropriate and effective measures to ensure equal enjoyment of human rights by Roma by further promoting equal access of Roma children to education, thereby contributing to prevent them from being engaged in the worst forms of child labor, and as well as to right to housing, health care and employment. A/HRC/18/30/Add.1 (SR Slavery, 2011).

#### **ILO Convention No. 138 related to the minimum age of employment:**

- Article 2(3). The minimum age specified in pursuance of paragraph 1 of this Article shall not be less than the age of completion of compulsory schooling and, in any case, shall not be less than 15 years.
- Article 3(1). The minimum age for admission to any type of employment or work which by its nature or the circumstances in which it is carried out is likely to jeopardize the health, safety or morals of young persons shall not be less than 18 years.
- Article 7(1). National laws or regulations may permit the employment or work of persons 13 to 15 years of age on light work which is: a) Not likely to be harmful to their health or development; and b) Not such as to prejudice their attendance at school, their participation in vocational orientation or training programs approved by the competent authority or their capacity to benefit from the instruction received.

**ILO Convention No. 182 (1999) concerning the Prohibition and Immediate Action for the Elimination of the Worst Forms of Child Labour**

## Table II: Children's Health and Freedom from Harmful Traditional Practices

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• State takes limited measures to prevent harmful traditional practices that are prejudicial to the health and well-being of children.</li> <li>• Female genital mutilation of young girls, and impunity for perpetrators.</li> <li>• Early and forced marriages of children.</li> <li>• Discrimination and abandonment of twins out of traditional belief that they are bad luck.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 24(3):</b> States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.</p>	<p><b>CRC Committee:</b> Expressing serious concern at the high prevalence of girls subjected to female genital mutilation (FGM) in <b>Egypt</b> and <b>Burkina Faso</b>, and particularly concerned at impunity for perpetrators. CRC/C/EGY/CO/3-4 (CRC, 2011), para. 68; CRC/C/BFA/CO/3-4 (CRC, 2010), para. 58.</p> <p><b>CRC Committee:</b> Recommending that <b>Bulgaria</b> closely collaborate with the minority communities and their respective leaders to elaborate effective measures to abolish traditional practices prejudicial to the health and well-being of children, such as early marriage. CRC/C/SR.1318 (CRC, 2008), para. 46.</p> <p><b>CRC Committee:</b> Recommending that <b>Syria</b> prohibit early and forced marriages and repeal the Personal Status Code provisions allowing the judge to lower the age of marriage of boys to 15 years and of girls to 13 years. CRC/C/SYR/CO/3-4 (CRC, 2012), para. 68.</p> <p><b>CRC Committee:</b> Noting with deep concern that in <b>Madagascar</b> there is continuing prevalence of harmful practices, including discrimination and abandonment of twins and forced marriage (molety). CRC/C/MDG/CO/3-4 (CRC, 2012), para. 53.</p>
<p><b>CEDAW 16(2):</b> The betrothal and the marriage of a child shall have no legal effect, and all necessary action, including legislation, shall be taken to specify a minimum age for marriage and to make the registration of marriages in an official registry compulsory.</p>	<p><b>CEDAW Committee, General Recommendation No. 19:</b> In some States there are traditional practices perpetuated by culture and tradition that are harmful to the health of women and children. These practices include dietary restrictions for pregnant women, preference for male children and female circumcision or genital mutilation." (11th Session, 1992), para. 19, 20.</p> <p><b>CEDAW Committee:</b> Calling on states to undertake awareness-raising measures throughout country on negative effects of early marriage on women's enjoyment of their human rights, especially rights to health and education. <b>Gambia</b> A/60/38(SUPP) (CEDAW, 2005), <b>Nepal</b> A/59/38(SUPP) (CEDAW, 2004), <b>Guatemala</b> A/57/38(SUPP) (CEDAW, 2002), <b>Algeria</b> CEDAW/C/DZA/CO/3-4 (CEDAW, 2012).</p> <p><b>CEDAW Committee:</b> Recommending that <b>Yemen</b> take urgent legislative measures to raise the minimum age of marriage for girls, stipulate that child marriages have no legal effects, and enforce the requirement to register all marriages in order to monitor their legality and the strict prohibition of early marriages. CEDAW/C/YEM/CO/6 (CEDAW, 2009).</p>

**Table II (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 10:</b> The States Parties to the present Covenant recognize that: (1) . . . Marriage must be entered into with the free consent of the intending spouses.</p> <p>(3) Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. Children and young persons should be protected from economic and social exploitation</p> <p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR General Comment 14(22):</b> There is a need to adopt effective and appropriate measures to abolish harmful traditional practices affecting the health of children, particularly girls, including early marriage, female genital mutilation, preferential feeding and care of male children.</p> <p><b>CESCR:</b> Expressing continued concern about the persistence of harmful traditional practices in <b>Nepal</b> that violate the rights of women and girls as deuki (dedicating girls to a god or goddess), badi (widespread practice of prostitution among the Badi caste), chaupadi (isolating a woman during menstruation because she is considered to be impure), marrying child brides, and witchcraft. E/C.12/NPL/CO/2 (CESCR, 2008).</p> <p><b>CESCR:</b> Expressing concern that child marriages still occur in <b>Turkmenistan</b>. E/C.12/TKM/CO/1 (CESCR, 2011).</p> <p><b>CESCR:</b> Recommending that <b>Kenya</b> adopt legislation criminalizing all female genital mutilation of adult women; continue promoting alternative rite of passage ceremonies; and combat traditional beliefs about the usefulness of female genital mutilation for the promotion of marriage prospects of girls. E/C.12/KEN/CO/1 (CESCR, 2008).</p>

**Other Interpretations**

**SR Violence against Women:** Recommending that **Afghanistan** ensure that the criminal law clearly establishes that those involved in organization of child and forced marriages commit a crime and must be prosecuted and punished. E/CN.4/2006/61/Add.5 (SR Violence against Women, 2006).

**SR Violence against Women:** Recommending that **Saudi Arabia** adopt guidelines for government agencies and religious leaders aimed at preventing and ending child and forced marriage; standardize the age of majority in the Kingdom at 18 in accordance with CRC, and ensure its application to the legal age of marriage. A/HRC/11/6/Add.3 (SR Violence against Women, 2009).

**SR Freedom of Expression:** Urging **Kyrgyzstan** to amend legislation to set a uniform minimum legal age for marriage at 18 for both women and men, in line with international standards. A/HRC/14/22/Add.2 (SR Freedom of Expression, 2010).

### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>82</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>83</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>84</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>85</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>82</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>83</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>84</sup> Ibid.

<sup>85</sup> Ibid.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>86</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>86</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.



## 4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF CHILDREN'S HEALTH AND HUMAN RIGHTS?

This section contains **five examples** of effective human rights-based work addressing health and human rights of children. These are:

1. Court in Bangladesh finding that corporal punishment in school is a violation of children's international human rights
2. European Court of Human Rights Protecting a Migrant Child from Forced Labor and Servitude in France
3. Longitudinal Study of War-Affected Youth (LSWAY) in Sierra Leone
4. National Children's Summits Realizing the Children's Right to Participate in Rwanda
5. Legal Advocacy for Children with Differences of Sex Development (DSD) or Intersex Conditions

## Example I: Court in Bangladesh finding that corporal punishment in school is a violation of children's international human rights

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### Project Type

Litigation: *Blast v. Secretary of the Ministry of Education and Others*, Supreme Court of Bangladesh, Writ Petition No.5684 of 210 (January 13, 2011).

### Actor

Bangladesh Legal Aid and Services Trust (BLAST) and Ain o Salish Kendro (ASK) have long established track records of undertaking public interest litigation in the interests of the most marginalized populations.

### Problem

Children studying in government and non-government primary and secondary education institutions in Bangladesh received corporal punishment from their teachers for offenses not recognized by law, including “not doing homework, failing to bring crayons to school, not saying prayers [and] having long hair.” The abuse was widespread and regular. According to a recent report by UNICEF: “most children in Bangladesh [were] regularly exposed to physical abuse at school, at home or where they work[ed] . . . .” Indeed, 91% of children surveyed in that study experienced various levels of physical abuse while at school. Also, the corporal punishment the children received was sometimes so horrendously violent that the child victim would require hospital treatment. Forms of corporal punishment included canning, beating, and the chaining of children.

Even in the absence of such especial violence—as the Court in this case noted—“There cannot be any doubt that corporal punishment is detrimental to children’s well-being and has serious physical, psychological and emotional effects, as well as causing truancy and dropping out of school. This in turn exacerbates the cycle of illiteracy and poverty.” Although the Penal Code did not authorize corporal punishment as a form of discipline and school regulations did not provide for it, the State systematically failed to adhere to the constitutional and statutory obligations to investigate allegations of corporal punishment. Teachers would simply pay the hospital bills of the students they battered and avoid criminal liability.

### Procedure

Before the Supreme Court of Bangladesh, High Court Division, pursuant to Article 102 of the Constitution of the People’s Republic of Bangladesh (providing original jurisdiction to the High Court Division to receive applications arising from fundamental constitutional rights).

“If we are to reach real peace in this world, and if we are to carry on a real war against war, we shall have to begin with children; and if they will grow up in their natural innocence, we won’t have to struggle, we won’t have to pass fruitless idle resolutions, but we shall go from love to love and peace to peace, until at last all the corners of the world are covered with that peace and love for which, consciously or unconsciously, the whole world is hanging.” – *Mahatma Gandhi, quoted by the CRC and the Court.*

## Arguments and Holdings

### *Constitutional Law*

The plaintiffs argued that the corporal punishment of school children violated the punishment provisions of the Bangladeshi Constitution. Clause 5 of Article 35, which protects the rights of citizens with respect to trial and punishment, provides that “no person shall be subject to torture or to cruel, inhuman or degrading punishment or treatment.” The Court found a violation of Article 35, reasoning that “it should be obvious that if any person is protected from ‘torture or . . . cruel, inhuman or degrading punishment treatment’ after conviction of a criminal offense, then it stands to reason that a child shall not be subjected to such punishment for behavior in school which cannot be termed criminal offense.”

### *Statutory Law*

The defendants argued that various national statutes affirmed the imposition of corporal punishment. Specifically, the Code of Criminal Procedure, the Prisoners Act (1894), Whipping Act (1909), Cantonment Pure Foods Act (1966), Suppression of Immoral Traffic Act (1933), Railways Act (1890), and the Children Rules (1976) all affirmatively provide for the imposition of corporal punishment. But none of these national statutes provided for corporal punishment in schools. The Court read these statutes narrowly and therefore concluded that they did not affirmatively call for the imposition of corporal punishment in schools. The Court also heard a statutory-based defense to corporal punishment. At first glance, section 89 of the Penal Code seemed to provide a defense for corporate punishment. The section provided that: “[n]othing which is done in good faith for the benefit of a person under twelve years of age, or of unsound mind, by or by consent . . . of the guardian . . . is an offense by reason of any harm which it may cause . . . .” However, as the Court rightly noted, the third proviso to section 89 explains “[t]hat this exception shall not extend to the voluntary causing of grievous hurt . . . unless it be for the purpose of preventing death or grievous hurt . . . .” Therefore, the Court found that section 89 did not excuse the imposition of corporal punishment.

### *Contract Law*

The defendants then raised the argument that a parent provided consent to the corporal punishment of their children by agreeing to send their children to school. The Court reasoned that, unless there was an express agreement to the contrary, the parents did not consent to the corporal punishment of their children. The agreement between the parent and the school was for the school to provide the parent’s child with an education. Therefore, this contract-based defense to corporal punishment also failed.

“The contents of the writ petition and the additional affidavits filed by the parties have exposed the dark and sinister side of education in Bangladesh. The details of some of the incidents have stirred our conscience and left us feeling distraught at the thought of parents allowing their children to be beaten and teachers mercilessly beating their pupils for small indiscretions. Most importantly, it is distressing to note that some of the incidents have led to fatality.” – *Md. Imman Ali, J., writing for the Court*

### *Foreign and International Law*

The Court declared the familiar precept that where there is no domestic law on point for the issue before the court, then the court should draw upon the international agreements entered into by the national government. Bangladesh had ratified that Convention on Rights of the Child (CRC), and the Court interpreted Article 28 of the CRC as prohibiting “corporal punishment upon the children . . . in all settings including schools, homes and work places.” The Court also looked to foreign law, noting that “[t]here are [were] numerous countries of this world, both advanced and less developed, who have adopted prohibition of corporal punishment both at home and in the education institutions.” Foreign and international law informed the Court’s understanding of the illegality of corporal punishment.

**Arguments and Holdings***Corporal Punishment at School*

The Court ordered that the Service Rules of the nation be amended to prohibit corporal punishment. A teacher who practices corporal punishment would be liable for misconduct under the amended Service Rules, as well as liable for all criminal offenses committed as part of administering corporal punishment. Corporal punishment at home and at the workplace.

**Convention on the Rights of the Child (CRC).**

Available at: [www2.ohchr.org/english/law/crc.htm](http://www2.ohchr.org/english/law/crc.htm)

- Article 19: Protection from abuse and neglect
- Article 28: Education
- Article 37: Torture and deprivation of liberty
- General Comment No. 8: The right of the child to protection from corporal punishment and other cruel or degrading forms of punishment

**Other Significant Treaties Affecting the Outcome of this Case**

- International Covenant on Civil and Political Rights.  
[www2.ohchr.org/english/law/ccpr.htm](http://www2.ohchr.org/english/law/ccpr.htm)
- Convention on the Prohibition on Torture and Other Forms of Cruel, Degrading and Unusual Treatment or Punishment. [www2.ohchr.org/english/law/cat.htm](http://www2.ohchr.org/english/law/cat.htm)
- Constitution of the People's Republic of Bangladesh.  
[www.wipo.int/wipolex/en/text.jsp?file\\_id=191720](http://www.wipo.int/wipolex/en/text.jsp?file_id=191720)

This was a sweeping and landmark decision by the Court. In addition to outlawing corporal punishment in schools across the nation, the Court recommended that the government amend the Children Act, 1974 to make it an offense for parents and employers to impose corporal punishment upon children. The Court also recommended the repeal of all existing domestic law allowing for the administration of corporal punishment, including whipping under the Penal Code, Code of Criminal Procedure, Railways Act, Cantonment Pure Food Act, Whipping Act, Suppression of Immoral Traffic Act, Children Rules, 1976 “and any other law which provides for whipping or caning of children and any other person.” “as being cruel and degrading punishment contrary to the fundamental rights guaranteed by the Constitution.”

**Ain o Salish Kendro**

Dhaka, Bangladesh

E-mail: [ask@citechco.net](mailto:ask@citechco.net)

Website: [www.askbd.org](http://www.askbd.org)

**Bangladesh Legal Aid Services Trust (BLAST)**

Dhaka, Bangladesh

E-mail: [mail@blast.org.bd](mailto:mail@blast.org.bd)

Website: [www.blast.org.bd](http://www.blast.org.bd)

## Example 2: European Court of Human Rights protecting a migrant child from forced labor and servitude in France

### Project Type

Litigation: *Siliadin v. France*, Judgment, merits and just satisfaction, App. No. 73316/01 (ECHR 2005).  
<http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-69891>

### Actor

Siwa-Akofa Siliadin, a Togolese national, represented by a legal aid attorney, H. Clément of the Paris Bar.

### Problem

Ms. Siliadin was born in 1978 and arrived in Paris on a tourist visa in 1994 at age 15. She arrived in Paris with “Mrs. D.” who promised to attend to her immigration status, find adequate schooling and let her work of the cost of her airfare by working at her home. Ms. Siliadin, however, ultimately became an unpaid housemaid for Mr. and Mrs. D. Also, her passport was taken from her. In the second half of 1994, Mrs. D. “lent” Ms. Siliadin to Mr. and Mrs. B. to perform household work for Mr. and Mrs. B.

While at Mr. and Mrs. B.’s home, Ms. Siliadin slept on a mattress on the floor in the baby’s room. She worked from 7:30 in the morning until 10:30 at night, seven days a week, performing a range of general household duties, without pay (except by Mrs. B.’s mother, who paid her one or two 500 French franc (FRF) notes).

On July 28, 1998, the police raided Mr. and Mrs. B.’s home. Mr. and Mrs. B. were charged with:

*...[H]aving obtained from July 1995 to July 1998 the performance of services without payment or in exchange for payment that was manifestly disproportionate to the work carried out, by taking advantage of that person’s vulnerability of state of dependence; [2] with having subjected an individual to working and living conditions that were incompatible with human dignity by taking advantage of her vulnerability or state of dependence....*

On June 10, 1999, the Paris *tribunal de grande instance* found that Mr. and Mrs. B. had taken advantage of a person’s vulnerability or dependent state to obtain services without payment or adequate payment. The Court, therefore, found Mr. and Mrs. B. guilty of Article 225-13 of the French Criminal Code. The Court sentenced the couple to a year imprisonment (with seven months suspended) and ordered them to pay, jointly and severally, FRF 100,000 to Ms. Siliadin.

The Court did not find, however, that Ms. Siliadin worked in conditions that were incompatible with human dignity. According to the court, working conditions violative of human dignity imply: “a furious pace, frequent insults and harassment, the need for particular physical strength that was disproportionate to the employee’s constitution and having to working unhealthy premises.” Therefore, since these conditions did not exist for Mr. Siliadin, Mr. and Mrs. B. did not create a work environment that was incompatible with human dignity.

**Procedure**

Mr. and Mrs. B. appealed the decision. On October 19, 2000, the Paris Court of Appeal acquitted Mr. and Mrs. B. of all criminal charges and dismissed all civil claims against them.

On December 11, 2001, the Court of Cassation quashed the decision of the Court of Appeal, but only with respect to the provisions dismissing the civil party's request for compensation in respect of the offences provided for in Articles 225-13 and 225-14 of the Criminal Code.

On May 15, 2003, the Versailles Court of Appeal, which ordered payment of 15,245 in compensation to Ms. Siliadin for the psychological trauma she experienced as a result of Mr. and Mrs. B.'s actions. On October 3, 2003, the Paris industrial tribunal awarded Ms. Siliadin back pay in the amount of €3,049.

Ms. Siliadin lodged an application with the European Court of Human Rights (ECtHR) on April 17, 2001, submitting that French criminal law lacked sufficient and effective protection. Her application was declared partly admissible on February 1, 2005.

**European Convention on Human Rights****Article 4.** Prohibition of slavery and forced labour

1. No one shall be held in slavery or servitude
2. No one shall be required to perform forced or compulsory labour.

**Convention Concerning Forced or Compulsory Labour****Article 2**

1. For the purposes of this Convention the term "forced or compulsory labour" shall mean all work or service which is exacted from any person under the menace of any penalty and for which the said person has not offered himself voluntarily.

**French Criminal Code**

**Art. 225-13:** "It shall be an offense punishable by two years' imprisonment and a fine of 500,000 francs to obtain from an individual the performance of services without payment or in exchange for payment that is manifestly disproportionate to the amount of work carried out, by taking advantage of that person's vulnerability or state of dependence."

**Arguments and Holdings**

Article 4 of the European Convention on Human Rights (ECHR) proscribes "slavery," "servitude" and "compulsory labor." The Court first looked to see if Ms. Siliadin was subjected to "slavery," "servitude" or "compulsory labor," and then turned to see if (a) French law proscribed that conduct, and (b) if the ECHR imposed a positive obligation on the French to criminalize such conduct.

*Forced or compulsory labor.* Drawing support from Article 2 of the Convention Concerning Forced or Compulsory Labor (1930), the Court interpreted the ECHR's reference to "forced or compulsory labour" to mean "all work or service which exacted from any person under the menace of any penalty and for which the said person has not offered himself voluntarily." Mr. and Mrs. B. had Ms. Siliadin labor for them without any compensation. Although they did not impose a penalty on her, she was a minor and feared arrest as an unlawfully present alien—the equivalent of a "penalty" by the Court's determination. Therefore, Ms. Siliadin was subjected to "forced labor" within the meaning of Article 4 of the ECHR.

*Servitude.* Citing a decision by a French court, the ECtHR interpreted servitude to mean “an obligation to provide one’s services that is imposed by the use of coercion.” Ms. Siliadin had not chosen to work for Mr. or Mrs. B. She was an alien minor. Mr. and Mrs. B. withheld her passport, and she feared arrest by the police. She had no resources and was vulnerable and isolated. The Court, therefore, held that Ms. Siliadin was held in servitude for purposes of Article 4 of the ECHR.

The ECtHR also pointed out that States Parties to the Supplementary Convention on the Abolition of Slavery, the Slave Trade, and Institutions and Practices Similar to Slavery—like France—had a positive obligation to take all practical and necessary legislative and other means to bring about progressively and as soon as possible the complete abolition or abandonment of, inter alia, debt bondage and serfdom.

*Slavery.*

Drawing support from Article 1(1) of the Slavery Convention, the Court interpreted “slavery” as found in the Article 4 of the ECHR to mean “ownership” of another. The Court held that, although Ms. Siliadin did not have freedom of movement, she did not suffer slavery, as Mr. and Mrs. B never exercised any genuine legal right of ownership of Ms. Siliadin.

*Positive obligation of France.*

Slavery and servitude were not expressly criminalized under French law. Articles 225-13 and 225-14 of the French Criminal Code (see box) contained ambiguities and gave rise to different interpretations by the national courts. Article 4 enshrines one of the most basic values of democratic societies. Not imposing a positive obligation on states to fashion domestic legislation in accordance with the article but rather only finding State Parties liable for state actions in violation of the article would result in ineffective protection of one of the most basic values within the Council of Europe. Therefore, France failed in its positive obligation under the ECHR to provide legal protection to Siliadin from slavery and forced labor.

## **Slavery, Servitude, Forced Labour and Similar Institutions and Practices Convention of 1926**

Article 1(1): Slavery is the status or condition of a person over whom any or all of the powers attaching to the right of ownership are exercised.

## **Supplementary Convention on the Abolition of Slavery, the Slave Trade, and Institutions and Practices Similar to Slavery (1956)**

Article 1: Each of the States Parties to this Convention shall take all practicable and necessary legislative and other measures to bring about progressively and as soon as possible the complete abolition or abandonment of . . . debt bondage . . . serfdom . . .

### **Commentary and Analysis**

This is the first case in which the ECtHR found a violation of Article 4. With the interpretative support of other international treaties, the Court found that Mr. and Mrs. B subjected Ms. Siliadin to forced labor and servitude, and thus strengthened protection against human trafficking and migrant forced labor within Europe.



## Example 3: Youth Readiness Intervention in Sierra Leone

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**Project Type:**

Advocacy/Capacity Building

**Organization:**

The François-Xavier Bagnoud (FXB) Center for Health and Human Rights at Harvard University is an interdisciplinary academic center that works to advance the rights and wellbeing of children, adolescents, youth and their families living in the most extreme circumstances worldwide. Founded in 1993, the Center works with local partners and communities to conduct and support research, teaching, advocacy, and targeted action in the areas of child protection and adolescent empowerment.

The FXB Center's Research Program on Children and Global Adversity (RPCGA) engages in applied research to contribute to stronger and evidence-based interventions to serve children and families in adversity worldwide. The RPCGA is involved in a variety of projects, including the Longitudinal Study of War-Affected Youth in Sierra Leone. Building on collaborations and research dating from 2002, the RCPGA has continued to advance its work with former child soldiers and other war-affected youth in Sierra Leone.

The longitudinal research has followed a cohort of over 500 girls and boys—many of them former child soldiers—from ages 10-17 into adulthood and now into an intergenerational phase. The longitudinal findings to date have been used to develop and evaluate the Youth Readiness Intervention in Sierra Leone and interest is growing to extend it to several other settings including northern Uganda, the DRC and Somalia.

**Problem**

Former child soldiers frequently experience high rates of emotional and behavioral problems (anger, hopelessness, high risk behavior) related to exposure to violence and loss. These issues may be exacerbated by post-conflict stressors, such as stigma, community distrust, poverty, poor educational opportunity, and limited community and social support. These challenges are particularly salient in Sierra Leone, which experienced a bloody 11-year conflict from 1991 to 2002. As many as 28,000 children and youth were engaged in war-related activities, including involvement with the Sierra Leone army, civilian defense forces and the Revolutionary United Front, the rebel group central to the conflict. Many young people witnessed, perpetrated and were subjected to acts of intense violence.

After the war, short-term disarmament, demobilization, and reintegration programs sought to prepare former child soldiers to return to their homes. During this process, many programs and sensitization campaigns emphasized that children had been forcibly involved in armed groups against their will. Nevertheless, returning youth were frequently treated with fear, distrust and stigma when they attempted to reintegrate. While tremendous resilience has been evidenced in this setting, for some youth, psychological trauma, problems with community stigma, interpersonal deficits and distrust placed many at risk for poor health and developmental outcomes, low rates of school completion, and limited economic self-sufficiency.

### **Actions Taken**

Longitudinal data collected in 2002, 2004 and 2008 indicate that more risky developmental trajectories and poor life outcomes are associated with a constellation of war-related toxic stress exposures (i.e. being forced to injure or kill others, sexual violence) and post-conflict stressors (stigma, poor access to school, loss of caregivers, poor social support). According to Dr. Theresa S. Betancourt, the principal investigator of LSWAY:

*"...[T]here are multiple influences on psychosocial adjustment and social reintegration for child soldiers. Certainly, individual-level war experiences, coping skills, and competencies matter, but outcomes are also strongly shaped by family community, and even larger macro-level factors such as the availability of education programs for youth who have missed many years of schooling due to war. Such enabling environments have a critical role to play in supporting the health adjustment of war affected youth."*

### **Results & Lessons Learned**

The RPCGA team has used its findings to design an integrated intervention for war-affected youth in Sierra Leone with strong links to job skills training and educational initiatives. The Youth Readiness Intervention is the first initiative to use epidemiological findings in the region to target the multiple problems areas and interrelated risk factors common in war-affected youth. It consists of six empirically-supported treatment components that have been shown to be effective for troubled youth in other settings (i.e. building skills in emotion regulation, coping and addressing interpersonal deficits).

The model has been evaluated in a recent randomized controlled trial conducted in August-October of 2012 which demonstrated significant improvements among youth receiving the YRI on outcomes of emotion regulation, daily functioning, social support and prosocial skills compared to a wait list control group. The research team has been working with local development funders and the Sierra Leone government to examine mechanisms for taking this evidence based intervention to scale.

Through targeted methods of participatory research, community engagement, and policy advocacy, such evidence-based readiness interventions have the potential to be systematically integrated into education and employment programs for young people affected by war and communal violence.

#### **François-Xavier Bagnoud Center for Health and Human Rights**

Longitudinal Study of War-Affected Youth (LSWAY)

Principal Investigator: Theresa S. Betancourt, Sc.D., M.A.

Website: [www.harvardfbcenter.org/research-program-on-children-and-global-adversity](http://www.harvardfbcenter.org/research-program-on-children-and-global-adversity)

## Example 4: National Children's Summits realizing the right to participation in Rwanda

### Project Type

Advocacy

### Organization

The Rwandan National Children's Summit has been held annually since 2004. It is a national forum with the children of Rwanda and policy makers in Rwanda's National Parliament. The Summit, organized by the National Children's Commission, in partnership with the Ministry of Gender and Family Promotion and UNICEF, has provided children with a special opportunity to express their views and wishes about their country's policies and programs, their rights, their country's economic and social development and the role of children and adolescents.

### Problem

Often children are limited or prevented from expressing their views, but "Evidence from around the world indicates that when children participate in decisions that affect them, are allowed to express their opinions freely, to access information and to form associations, they can make a great contribution to transformation and social change."<sup>87</sup>

### International Protection for Children's Right to Participate

CRC Art. 12(1): States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

### Kenyan Protection for Children's Right to Participate

Law No. 27/2001, Art. 9: "The child's interests must be taken into account before any decision concerning him/her is made. It is a right for the child to express his/her opinion on any matter regarding him/her. It is necessary to hear from the child prior to making any decision concerning him/her regarding administrative and judicial matters whether directly or indirectly through his/her representative."

### Actions Taken

Born out of the 10th Commemoration of the Rwandan Genocide, which offered children an opportunity to reflect on the lasting consequences of the national and human tragedy, the National Children's Summit institutionalized a platform for social dialogue between decision-makers and children.

<sup>87</sup> Statement by Murakoze Cyane, UNICEF Representative for Rwanda. Available at: [www.unicef.org/rwanda/RWA\\_statement\\_skinnerRCS.pdf](http://www.unicef.org/rwanda/RWA_statement_skinnerRCS.pdf)

The National Children's Summit, held annually in the nation's capital of Kigali, is the culmination of consultations, which take place throughout the year with children at the sector (local) and district levels. Elected child representatives from each of the 416 sectors gather the views of children and present them at the National Summit. In 2012, for the first time, special care was taken to ensure that child delegates to the Summit represented vulnerable children, including children with disabilities, children from refugee camps, street children and orphans. Policymakers and government officials in attendance at the Summit included the prime minister, the ministers of Education, Gender and Family Promotion; Governors; faith-based leaders and mayors/vice mayors of several districts. The Summit themes, which are chosen by children themselves, have focused on unity and reconciliation; a Rwanda fit for children; children and the country's development plan; the role of children in fighting genocide ideology; the role of children in fighting violence against children; education fit for children; and how children can contribute to the nation's second *Economic Development and Poverty Reduction Strategy* (EDPRS).

### Results and Lessons Learned

As a result of the National Children's Summits, the recommendations of children have been integrated into Rwanda's first EDPRS as well as the work of the Unity and Reconciliation Commission. Direct dialogue with policymakers ensures that the actions of States are ever more sensitive to the implementation of children's rights.

#### Additional Resources

Ministry of Gender and Family Protection: [www.migeprof.gov.rw](http://www.migeprof.gov.rw)

UNICEF: [www.unicef.org/infobycountry/rwanda\\_61272.html](http://www.unicef.org/infobycountry/rwanda_61272.html)

## Example 5: Legal advocacy for children with differences of sex development (DSD) or intersex conditions

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### Project Type

Advocacy

### Organization

Advocates for Informed Choice (AIC) is the only organization in the US to undertake a coordinated strategy of legal advocacy for the rights of children with differences of sex development (DSD) or intersex conditions. DSD or intersex conditions are congenital variations of chromosomal, gonadal, and/or anatomical sex.

### Problem

People worldwide born with DSD or intersex conditions face a wide range of violations to their sexual and reproductive rights, as well as the rights to bodily integrity and individual autonomy. Infants and children with DSD or intersex conditions are often subject to irreversible sex assignment and involuntary cosmetic genital-normalizing surgery in an attempt to make their bodies more typical. Intersex individuals suffer life-long physical and emotional injuries as a result of such treatment, including sterility, pain, loss of genital sensation and function, and depression. Many children with DSD or intersex conditions continue to undergo involuntary genital surgery.

### Actions Taken

- AIC used conferences and academic lectures to raise awareness and advocate on behalf of the rights of intersex children.
- In April 2012, Anne Tamar-Mattis, Executive Director of AIC, published an article in the *California Law Review Journal* on “Sterilization and Minors with Intersex Conditions in California Law.” The article calls on California to adapt its procedural framework for protecting the reproductive rights and the best interests of incompetent patients to fit the situation of children with intersex conditions. ([www.californialawreview.org/articles/sterilization-and-minors-with-intersex-conditions-in-california-law](http://www.californialawreview.org/articles/sterilization-and-minors-with-intersex-conditions-in-california-law))
- In October 2012, AIC was invited to present at the World Health Organization (WHO) on forced sterilization of intersex children, in preparation for its upcoming report on Involuntary Sterilization.
- In December 2012, AIC submitted a report to the UN Special Rapporteur on Torture on “Medical Treatment of People with Intersex Conditions as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment.” The report described violations experienced by people with intersex conditions in healthcare settings, including cosmetic genital-normalizing surgery, involuntary sterilization, excessive genital exams and medical display, human experimentation and denial of needed medical care.
- In 2008-2010, AIC worked with an intersex woman who underwent genital surgery as a child to receive an official apology for the woman from two leading hospitals and the physician who had overseen her care. This is the first apology of its kind. ([www.opensocietyfoundations.org/voices/why-are-doctors-still-performing-genital-surgery-on-infants](http://www.opensocietyfoundations.org/voices/why-are-doctors-still-performing-genital-surgery-on-infants))

### Results and Lessons Learned

- In its 2012 report, “Born Equal and Free: Sexual Orientation and Gender Identity in International Human Rights Law,” the UN recognized human rights violations against children with intersex/DSD: “In addition, intersex children, who are born with atypical sex characteristics, are often subjected to discrimination and medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to fix their sex.” ([www.ohchr.org/Documents/Publications/BornFreeAndEqualLowRes.pdf](http://www.ohchr.org/Documents/Publications/BornFreeAndEqualLowRes.pdf))
- In 2013, the UN Special Rapporteur on Torture, Juan Mendez, released a powerful statement calling for an end to forced genital-normalizing surgery and medical display: “The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, [or] medical display ... when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.”
- In 2013, AIC was invited to testify in front of the Inter-American Commission on Human Rights on issues of involuntary genital surgery. The Inter-American Commission on Human Rights created a unit on the Rights of Lesbian, Gay, Bisexual, Trans and Intersex Persons in 2011.
- A human rights approach to legal advocacy allows for a wider scope of influence, especially when traditional legal mechanisms are ineffective.

#### **Advocates for Informed Choice**

Cotati, California, United States

Website: <http://aiclegal.org/>

Facebook: [www.facebook.com/aiclaws](http://www.facebook.com/aiclaws)

## 5. WHERE CAN I FIND ADDITIONAL RESOURCES ON HEALTH AND HUMAN RIGHTS OF CHILDREN?

A list of commonly used resources on children's health and human rights follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Human Rights and Children – General Resources
- D. Right to Health
- E. Right to Life, Survival and Development
- F. Right to Express Views
- G. Right to Information; Right to Sexual and Reproductive Health and Education
- H. Right to Education
- I. Right to Adequate Standard of Living and Social Security Services
- J. Freedom from Abuse, Torture and Ill-treatment
- K. Freedom from Economic or Social Exploitation
- L. Freedom from Harmful Traditional Practices
- M. Key Populations – Children with Disabilities
- N. Key Populations – Children Living with HIV
- O. Key Populations – Children with Stateless and Migrating Children
- P. Key Populations – Children in Conflict with the Law
- Q. Websites



## A. International Instruments

### Binding

- International Labour Organization, *Convention concerning Minimum Age for Admission to Employment*, No. 138 (1973). [www.ilocarib.org.tt/projects/cariblex/conventions\\_6.shtml](http://www.ilocarib.org.tt/projects/cariblex/conventions_6.shtml).
- International Labour Organization, *Convention concerning the Prohibition and Immediate Action for the Elimination of the Worst Forms of Child Labour*, No. 182 (1999). [www.ilocarib.org.tt/projects/cariblex/conventions\\_9.shtml](http://www.ilocarib.org.tt/projects/cariblex/conventions_9.shtml).
- UN General Assembly, *Convention on the Rights of the Child*, Resolution 44/25, A/44/49 (1989). [www.unicef.org/crc/](http://www.unicef.org/crc/).
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- UN General Assembly, *Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography*, Resolution 54/263, UN Doc. A/54/49, Vol. III (2000). <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OPSCCRC.aspx>
- UN General Assembly, *Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children, Supplementing the United Nations Convention against Transnational Organized Crime* (2000). [www.unodc.org/unodc/en/treaties/CTOC/index.html](http://www.unodc.org/unodc/en/treaties/CTOC/index.html).

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- UN Committee on the Rights of the Child, Decisions. [www2.ohchr.org/english/bodies/crc/decisions.htm](http://www2.ohchr.org/english/bodies/crc/decisions.htm).
  - *Children in armed conflict*, no. 1 (1998); *Administration of juvenile justice*, no. 2 (1999); *Children without parental care*, no. 7 (2004).
- UN Committee on the Rights of the Child, General Comments. [www2.ohchr.org/english/bodies/crc/comments.htm](http://www2.ohchr.org/english/bodies/crc/comments.htm).
  - *The aims of education*, no. 1 (2001); *The role of independent human rights institutions*, no. 2 (2002); *HIV/AIDS and the rights of the child*, no. 3 (2003); *Adolescent Health*, no. 4 (2003); *General measures of implementation for the Convention on the Rights of the Child*, no. 5 (2003); *Treatment of unaccompanied and separated children outside their country of origin*, no. 6 (2005); *Implementing child rights in early childhood*, no. 7/Rev.1 (2005); *The right of the child to protection from corporal punishment and other cruel or degrading forms of punishment*, no. 8 (2006); *The rights of children with disabilities*, no. 9 (2006); *Children's rights in Juvenile Justice*, no. 10 (2007); *Indigenous children and their rights under the Convention*, no. 11 (2009); *The right of the child to be heard*, no. 12 (2009); *The right of the child to freedom from all forms of violence*, no. 13 (2011); *The right of the child to the enjoyment of the highest attainable standard of health (Article. 24)*, no. 15 (2013); *On State obligations regarding the impact of the business sector on children's rights*, no. 16 (2013); and *The right of the child to rest, leisure, play, recreational activities, cultural life and the arts*, no. 17 (2013).
- UN Committee on the Rights of the Child, Recommendations. <http://www2.ohchr.org/english/bodies/crc/discussion.htm>.

- *Children in armed conflict* (1992); *Economic exploitation* (1993); *Role of the family* (1994); *The girl child* (1995); *Juvenile justice* (1995); *The child and the media* (1996); *Children with disabilities* (1997); *HIV/AIDS* (1998); *10th Anniversary: General measures of implementation* (1999); *State violence against children* (2000); *Violence against children within the family and in school* (2001); *The private sector as a service provider* (2002); *The rights of indigenous children* (2003); *Implementing child rights in early childhood* (2004); *Children without parental care* (2005); *The right of the child to be heard* (2006); *Resources for the Rights of the Child: Responsibility of States* (2007); *The right of the child to education in emergency situations* (2008).
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  - *United Nations Millennium Declaration, Resolution 55/2* (September 18, 2000).
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- WHO, *Female Genital Mutilation: A Joint WHO/UNICEF/UNFPA Statement* (July 1997). [www.un.org/women-watch/daw/csw/csw52/statements\\_missions/Interagency\\_Statement\\_on\\_Eliminating\\_FGM.pdf](http://www.un.org/women-watch/daw/csw/csw52/statements_missions/Interagency_Statement_on_Eliminating_FGM.pdf).

## B. Regional Instruments

### *Binding*

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## C. Human Rights & Children - General Resources

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- US Library of Congress, "Children's Rights: International and National Laws and Practices". [www.loc.gov/law/help/child-rights/index.php](http://www.loc.gov/law/help/child-rights/index.php).
- Van Bueren G, *The International Law on the Rights of the Child* (Netherlands: Kluwer Law International, 1998).

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- International Society for the Prevention of Child Abuse and Neglect (ISPCAN): [www.ispcan.org](http://www.ispcan.org).
- Latin American and Caribbean Network for Children / Red Latinoamericana y caribera por la defensa de los derechos de los niños, niñas y adolescentes (REDLAMYC): [www.redlamyc.info](http://www.redlamyc.info).
- Millennium Development Goals: [www.un.org/millenniumgoals](http://www.un.org/millenniumgoals).
- Partnership for Maternal, Newborn & Child Health (PMNCH): [www.pmnch.org](http://www.pmnch.org).
- Plan International: [www.planusa.org](http://www.planusa.org).
  - Because I Am A Girl campaign: [www.becauseiamagirl.ca](http://www.becauseiamagirl.ca).
- Population Council, "Poverty, Gender and Youth": [www.popcouncil.org/what/pgy.asp](http://www.popcouncil.org/what/pgy.asp).
- Save the Children: [www.savethechildren.org](http://www.savethechildren.org).
- Terre des Hommes International Federation: [www.terredeshommes.org](http://www.terredeshommes.org).
- UNESCO, "Youth": [www.unesco.org/new/en/social-and-human-sciences/themes/youth](http://www.unesco.org/new/en/social-and-human-sciences/themes/youth).
- UNICEF: [www.unicef.org](http://www.unicef.org).
  - ChildInfo: [www.childinfo.org](http://www.childinfo.org).
  - Innocenti Research Centre (IRC): [www.unicef-irc.org](http://www.unicef-irc.org).
- UN Population Fund (UNFPA): [www.unfpa.org](http://www.unfpa.org).
- United Nations
  - International Day of the Girl Child (11 October): [www.un.org/en/events/girlchild](http://www.un.org/en/events/girlchild).
  - International Year of Youth: August 2010–2011: <http://social.un.org/youthyear>.
- World Health Organization (WHO)
  - Global Strategy for Women and Children's Health: [www.who.int/pmnch/activities/jointactionplan](http://www.who.int/pmnch/activities/jointactionplan).
  - Health Metrics Network: [www.who.int/healthmetrics](http://www.who.int/healthmetrics).
- Youth RISE: [www.youthrise.org](http://www.youthrise.org).

## 6. WHAT ARE KEY TERMS RELATED TO CHILDREN'S HEALTH AND HUMAN RIGHTS?

### A

#### *Adolescent*

Any individual aged between 10-19 years

---

### B

#### *Best Interests of the Child*

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

---

### C

#### *Child*

All human beings under the age of 18 unless the relevant national law recognizes an earlier age of majority.

#### *Child Labor*

Children work for a variety of reasons in differing cultural, social and economic circumstances. Whether work is defined as exploitative will depend on a range of factors including the work itself, the work environment, the presence of particular hazards, the perceived benefits of work and the nature of the employment relationship.

---

### D

#### *Development Rights*

The rights enabling children to reach their fullest potential (e.g. education, play and leisure, cultural activities, access to information and freedom of thought, conscience and religion).

---

### J

#### *Juvenile Justice*

Children and adolescents held in custody for crimes may suffer torture and inhumane and degrading treatment; they may be unlawfully detained and be denied their right to a fair trial. They may be given sentences which damage their well-being and prevent their successful re-integration into society. The administration of juvenile justice is carried out in accordance with the best interests of the child.

---

### M

#### *Military Recruitment*

An estimated 300,000 children and adolescents are engaged in armed conflict and are often forced into committing extremely brutal acts of violence. Children have a right to specific protection in situations of armed conflict.

## **N**

### ***Non-Discrimination***

Each child's rights are ensured without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, color, sex, language, religion, political or other opinion, national, ethnic, or social origin, property, disability, birth, or other status.

---

## **P**

### ***Participation***

Children who are capable of forming his or her own views have the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

### ***Participation Rights***

Rights that allow children and adolescents to take an active role in their communities (e.g., the freedom to express opinions; to have a say in matters affecting their own lives; to join associations).

### ***Protection Rights***

Rights that are essential for safeguarding children and adolescents from all forms of abuse, neglect and exploitation (e.g., special care for refugee children; protection against involvement in armed conflict, child labor, sexual exploitation, torture and drug abuse).

---

## **S**

### ***Sexual Exploitation***

Sexual abuse and exploitation can take a variety of forms including rape, commercial sexual exploitation, and domestic abuse.

### ***Survival rights***

The right to life and to have the most basic needs met (e.g., adequate standard of living, shelter, nutrition, medical treatment).

---

## **Y**

### ***Young Person***

Any individual between 10-24 years.

### ***Youth***

Any individual between the ages of 15-24.



# CHAPTER 7



## MINORITY HEALTH AND HUMAN RIGHTS

“Ending discrimination against minorities requires us to protect and embrace diversity through the promotion and implementation of human rights standards.”

— *Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, OHCHR Booklet Introduction*

## **Health and Human Rights Resource Guide**

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Cover photograph courtesy Bjorn Steinz – Panos, Open Society Foundations, “Romina talks with Ljutvia, a mother of eight during European Immunization Week in Vinica, Macedonia”

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# INTRODUCTION

This chapter will introduce you to key health and human rights issues facing minority populations.

The chapter is organized into eight sections that answer the following questions:

1. How is minority health a human rights issue?
2. What are the most relevant international and regional human rights standards related to minority health?
3. What is a human rights-based approach to advocacy, litigation, and programming?
4. What are some examples of effective human rights-based work in the area of minority health?
5. What steps can government and key stakeholders take to improve the health status of minority populations?
6. Where can I find additional resources on minority communities, health and human rights?
7. Where can I find additional resources on indigenous communities, health and human rights?
8. What are key terms related to minority health and human rights?

# I. HOW IS MINORITY HEALTH A HUMAN RIGHTS ISSUE?

## What do we mean by marginalized minority populations?

In this chapter, minority is used as an umbrella term to refer to marginalized ethnic, racial, cultural, and linguistic minorities as well as indigenous people. There is no internationally agreed-upon definition as to which groups constitute minorities or indigenous populations. This chapter will use these terms broadly, focusing on the marginalization of minorities and the effect of marginalization upon their health and human rights.

In 1979, the former Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, Francesco Capotorti, provided one of the most widely accepted definitions of minorities:

*A group numerically inferior to the rest of the population of a state, in a non-dominant position, where members—being national of the state—possess ethnic, religious, linguistic characteristics differing from those of the rest of the population and show, if only implicitly, a sense of solidarity, directed towards preserving their culture, tradition, religion or language.*<sup>1</sup>

The UN Minorities Declaration, adopted by the General Assembly in 1992, contains a more general definition of minorities, stating that minorities are persons belonging to national or ethnic, cultural, religious, and linguistic minorities.<sup>2</sup> The Office of the High Commissioner of Human Rights (OHCHR) stated that “[t]he difficulty in arriving at an acceptable definition lies in the variety of situations in which minorities exist.”<sup>3</sup> The OHCHR further states:

*It is often stressed that the existence of a minority is a question of fact and that any definition must include both objective factors (such as the existence of a shared ethnicity, language or religion) and subjective factors (including that individuals must identify themselves as members of a minority).*<sup>4</sup>

There has also been extensive discussion relating to indigenous peoples, but the United Nations has yet to adopt any definition.

## What are the issues and how are they human rights issues?

Minorities are among the most marginalized groups in society and experience higher rates of mortality, limited access to health services, and poorer health outcomes. Marginalization, social exclusion, and stigma, as well as other social and economic determinants like unemployment and poor material circumstances, affect access to health services and health status. A human rights-based approach that addresses social and economic determinants of health, including discrimination, is required to address the persistent inequalities of minority populations in health status and access to health.

1 Capotorti F, *Study on the Rights of Persons Belonging to Ethnic, Religious and Linguistic Minorities*, U.N. Doc E/CN.4/Sub.2/384/Rev.1, U.N. Sales No. E.78.XIV.1 (1979): 96.

2 UN General Assembly, *Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities*, U.N. Doc. A/RES/47/135 (Dec 18, 1992). [www.un.org/documents/ga/res/47/a47r135.htm](http://www.un.org/documents/ga/res/47/a47r135.htm).

3 UN Office of the High Commissioner for Human Rights (OHCHR), *Minority Rights*, Fact Sheet No.18 (Rev.1), [www.ohchr.org/Documents/Publications/FactSheet18rev.1en.pdf](http://www.ohchr.org/Documents/Publications/FactSheet18rev.1en.pdf).

4 OHCHR, *Minority Rights: International Standards and Guidance for Implementation* (2010). [www.ohchr.org/Documents/Publications/MinorityRights\\_en.pdf](http://www.ohchr.org/Documents/Publications/MinorityRights_en.pdf).

Minority populations are also more vulnerable to pandemic diseases such as HIV/AIDS and tuberculosis.<sup>5</sup> For more information on HIV/AIDS and minorities please see Chapter 2 on HIV, AIDS, and human rights. For more information on tuberculosis and minorities, please see Chapter 3 on Tuberculosis and human rights.

### Right to non-discrimination and equality before the law

Discrimination against minority populations remains a central problem and affects the enjoyment of all rights, including health. International human rights law prohibits discrimination on the basis of race, color, language, national or social origin, or other status. The International Convention on the Elimination of all forms of Racial Discrimination (ICERD) defines racial discrimination as “any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin” that impairs the enjoyment of human rights and fundamental freedoms. Likewise, prohibition against discrimination on the basis of race, color, language, national or social origin, or other status is listed in the International Covenant on Economic, Social and Cultural Rights (ICESCR), the International Covenant on Civil and Political Rights (ICCPR) and the Convention on the Rights of the Child (CRC). These human rights instruments require state parties to take all appropriate means to eliminate discrimination and to ensure that all public authorities and institutions conform with this obligation.

### Right to health

The right to health is expressly recognized in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which notes “The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”<sup>6</sup> Article 5 of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) also states:

*States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of... [inter alia, t]he right to public health, medical care, social security and social services.<sup>7</sup>*

However, minority and indigenous populations face disproportionate barriers to realizing the right to health. They often face limited access to health services and experience increased illness and greater mortality relative to majority populations in the same region and socioeconomic class. Likewise, indigenous peoples are often marginalized and “are poorer, less educated, die at a younger age, are much more likely to commit suicide, and are generally in worse health than the rest of the population.”<sup>8</sup> For example, according to the World Health Organization (WHO):

*In some regions of Australia, the Aboriginal and Torres Strait Islanders have a diabetes prevalence rate as high as 26%, which is six-times higher than in the general population. Among Inuit youth in Canada, suicide rates are among the highest in the world, at eleven-times the national average. For ethnic minorities in Viet Nam, more than 60% of childbirths take place without prenatal care compared to 30% for the Kinh population, Viet Nam’s ethnic majority.<sup>9</sup>*

5 UN Office of the High Commissioner for Human Rights, *Towards Developing Country Engagement Strategies on Minorities: An Information Note for OHCHR Staff and Other Practitioners*. [www.ohchr.org/Documents/Publications/Strategies\\_on\\_minoritiesEN.pdf](http://www.ohchr.org/Documents/Publications/Strategies_on_minoritiesEN.pdf).

6 International Covenant on Economic, Social and Cultural Rights (ICESCR). <http://www2.ohchr.org/english/law/cescr.htm>.

7 International Convention on the Elimination of all forms of Racial Discrimination (ICERD). <http://www2.ohchr.org/english/law/cerd.htm>.

8 World Health Organization (WHO), *Health of indigenous peoples* (Oct. 2007). [www.who.int/mediacentre/factsheets/fs326/en/index.html](http://www.who.int/mediacentre/factsheets/fs326/en/index.html).

9 Ibid.



Studies have shown that minority and indigenous populations have lower access to health services, health information, and adequate housing and safe drinking water than the general population. Children, in particular, have a higher mortality rate and are more likely to suffer from severe malnutrition.<sup>10</sup>

**Health care facilities, goods, and services**

The Committee on Economic, Social and Cultural Rights (CESCR) has expressly addressed minority populations in General Comment 14 on the right to health:

*States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including . . . minorities . . . to preventive, curative and palliative health services; [and] abstaining from enforcing discriminatory practices as a State policy.*<sup>11</sup>

The CESCR states that governments have a legal obligation to eliminate and abstain from all discriminatory practices in health care delivery to minorities. Similarly, the UN Special Rapporteur on the Right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Special Rapporteur on the right to health) also writes that states have a legal obligation “to ensure that a health system is accessible to all without discrimination, including ... minorities [and] indigenous peoples.”<sup>12</sup> The human rights principles of discrimination and equality require that states take affirmative action, for example through outreach programs, to ensure that minorities have the same access to health care in practice as others.<sup>13</sup>

CESCR General Comment 14 explains that the right to health requires States to ensure that minorities have physical accessibility to health facilities:

*[H]ealth facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ethnic minorities and indigenous populations . . .*<sup>14</sup>

This is particularly relevant for minority populations that are geographically isolated or are predominantly living in rural locations. Under this obligation, States are obligated to ensure that health facilities are provided in “safe physical reach.”

Under the right to health, facilities must be provided in a medically ethical and culturally appropriate manner. General Comment 14 explains that “culturally appropriate” includes “respectful of the culture of individuals, minorities, peoples and communities . . . as well as being designed to respect confidentiality and improve the health status of those concerned.”<sup>15</sup>

10 United Nations Office of the High Commissioner for Human Rights and the World Health Organization, *The Right to Health*, Fact Sheet No.31. [www.ohchr.org/Documents/Publications/Factsheet31.pdf](http://www.ohchr.org/Documents/Publications/Factsheet31.pdf).

11 UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14*, E/C.12/2000/4 (Aug. 11, 2000).

12 UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/7/11 (Jan. 31, 2008).

13 UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health* (Paul Hunt), A/HRC/7/11 (Jan. 31, 2008).

14 UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, E/C.12/2000/4, para. 12(b)(ii) (Aug. 11, 2000).

15 UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, E/C.12/2000/4 (Aug. 11, 2000), para. 12(b)(ii).

### ***Social and economic determinants of health***

In General Comment 14, CESCR explains that the right to health is “an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.”<sup>16</sup> Moreover, the determinants of health must also be physically accessible, economically affordable, and available in sufficient quantity and provided in a non-discriminatory manner.<sup>17</sup>

The determinants of health, as described above, “are in turn shaped by a wider set of forces: economics, social policies, and politics.”<sup>18</sup> Michael Marmot explains that “material deprivation is not simply a technical matter of providing clean water or better medical care. Who gets these resources is socially determined.”<sup>19</sup> Minorities, as a marginalized population, are more vulnerable to the social and economic determinants of health and consequently experience poorer health outcomes. As Richard Wilkinson and Michael Marmot explain, “It’s not simply that poor material circumstances are harmful to health; the social meaning of being poor, unemployed, socially excluded, or otherwise stigmatized also matters.”<sup>20</sup>

### **Rights of women**

Minority women are particularly vulnerable to multiple forms of discrimination because they bear the double burden of both gender and minority stigma. CERD explains:

*Racial discrimination does not always affect women and men equally or in the same way. There are circumstances in which racial discrimination only or primarily affects women, or affects women in a different way, or to a different degree than men. Such racial discrimination will often escape detection if there is no explicit recognition or acknowledgement of the different life experiences of women and men, in areas of both public and private life.*<sup>21</sup>

Minority women especially face barriers to education and full participation in the economic, cultural, political, and social life of their communities and in society.<sup>22</sup> In many places, minority women receive fewer health and reproductive health services, less information and are more vulnerable to physical and sexual violence.<sup>23</sup>

### ***Reproductive and sexual health***

Minority women face sexual and reproductive health rights violations from within their own communities, such as pressure to abstain from using contraception or to marry early, as well as from discriminatory policies aimed at women from particular minority groups, such as forced sterilization. For example, a study conducted by the Center for Reproductive Rights found that Romani women face widespread human rights violations, specifically reproductive rights violations. Violations include coerced or forced sterilization, misinformation in reproductive health matters, physical and verbal abuse by medical providers, racially

16 Ibid.

17 Ibid.

18 World Health Organization, *Social determinants of health: Key concepts*. [www.who.int/social\\_determinants/thecommission/finalreport/key\\_concepts/en/index.html](http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/index.html).

19 Marmot M, “Social determinants of health inequities,” *Lancet* 365 (2005) 1099–1104. [www.who.int/social\\_determinants/strategy/Marmot-Social%20determinants%20of%20health%20inqualities.pdf](http://www.who.int/social_determinants/strategy/Marmot-Social%20determinants%20of%20health%20inqualities.pdf).

20 Wilkinson R and Marmot M, “Social determinants of health: the solid facts” (2003). [www.euro.who.int/\\_\\_data/assets/pdf\\_file/0005/98438/e81384.pdf](http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf).

21 UN Committee on the Elimination of Racial Discrimination (CERD), *General Recommendation No. 25: Gender related dimensions of racial discrimination* (Mar. 20, 2000).

22 UN Office of the High Commissioner for Human Rights, *United Nations Forum on Minority Issues: Compilation of Recommendations of the First Four Sessions 2008-2011*. [http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum\\_On\\_Minority\\_Pub\\_en\\_low.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum_On_Minority_Pub_en_low.pdf).

23 United Nations Office of the High Commissioner for Human Rights and the World Health Organization, *The Right to Health*, Fact Sheet No.31. [www.ohchr.org/Documents/Publications/Factsheet31.pdf](http://www.ohchr.org/Documents/Publications/Factsheet31.pdf).

discriminatory access to health care resources and treatment, and denial of access to medical records.<sup>24</sup>

The European Court of Human Rights has heard cases on Roma women being sterilized without their full and informed consent. Usually, these procedures are conducted while the patient is in the hospital and undergoing another procedure. Below is an excerpt from a blog, explaining the process of surgical sterilization on Roma women:

*Between 1971 and 1991 in Czechoslovakia, now Czech Republic and Slovakia, the “reduction of the Roma population” through surgical sterilization, performed without the knowledge of the women themselves, was a widespread governmental practice. The sterilization would be performed on Romani women without their knowledge during Caesarean sections or abortions. Some of the victims claim that they were made to sign documents without understanding their content. By signing these documents, they involuntarily authorized the hospital to sterilize them. In exchange, they sometimes were offered financial compensation or material benefits like furniture from Social Services – though it was not explicitly stated what this compensation was for. The justification for sterilization practices according to the stakeholders was “high, unhealthy” reproduction.<sup>25</sup>*

In two recent cases, the European Court of Human Rights held that the sterilization of Roma women without their full and informed consent violated the women’s right to privacy.<sup>26</sup>

Minority women are especially vulnerable to systematic sexual violence, such as targeted rape. During armed conflicts, minority women can suffer from systematic sexual and other violence because of their ethnic, religious, tribal, or indigenous identity. Systematic violence against minority women during conflict was reported in conflicts, including Iraq, Afghanistan, Somalia, Sudan, Democratic Republic of Congo, Sri Lanka, Colombia, Guatemala, Kyrgyzstan, and Burma. Unfortunately, minority women often have limited or no access to justice and face discrimination from the police force and judicial system,<sup>27</sup> and are therefore unable to seek redress for these gross human rights violations.

### **Access to health care**

Poverty, remote geographic location, language barriers, and inaccessibility of health care prevent minority women from accessing and using health and reproductive health services. In some cases, minority women may be refused health services, receive inferior care, or be abused by health workers due to discrimination against minorities.<sup>28</sup> As a result, minority women are vulnerable to health and reproductive issues. For example, the Karen ethnic minority group in Thailand has one of the highest maternal mortality rates in the country. The Special Rapporteur on the right to health writes that the “burden of maternal mortality falls disproportionately on women in developing countries [and that] in both developing and developed countries, the burden of maternal mortality falls disproportionately on ethnic minority women, indigenous women and women living in poverty.”<sup>29</sup>

24 Center for Reproductive Rights, *Body and Soul: Forced Sterilization and other Assaults on Roma Reproductive Freedom in Slovakia* (2003). [http://reproductiverights.org/sites/default/files/documents/bo\\_slov\\_part1.pdf](http://reproductiverights.org/sites/default/files/documents/bo_slov_part1.pdf).

25 Stoyanova G, *Forced sterilization of Romani women – a persisting human rights violation*, (Romedia Foundation, February 7, 2013). <http://romediafoundation.wordpress.com/2013/02/07/forced-sterilization-of-romani-women-a-persisting-human-rights-violation/>.

26 Case of V.C. v. Slovakia, 18968/07 (Nov. 8, 2011) and Case of N.B. v. Slovakia, 29518/10 (June 12, 2012).

27 Minority Rights Group International, *Minority women deliberately targeted for rape and other violence – new global report* (July 6, 2011). [www.minorityrights.org/10851/press-releases/minority-women-deliberately-targeted-for-rape-and-other-violence-new-global-report.html](http://www.minorityrights.org/10851/press-releases/minority-women-deliberately-targeted-for-rape-and-other-violence-new-global-report.html).

28 Minority Rights Group International, *State of the World’s Minorities and Indigenous Peoples 2011* (2011). [www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html](http://www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html).

29 UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/HRC/4/28 (Human Rights Council, Jan 17., 2007).

Minority women are more likely to be living in poverty and are therefore less likely to have access to care, less likely to have routine care, and more likely to delay care. Poverty can also exacerbate reproductive health problems and can lead to poor nutrition and stress. “Poverty remains one of the most significant barriers to the full actualization of reproductive health, and the link between health, income and minority status is well established.”<sup>30</sup>

### Freedom from harmful cultural practices

Tension exists between rights of minorities and indigenous peoples to maintain their cultural identity and practice their culture, and the rights of women to be free from harmful cultural practices, such as female genital mutilation (FGM). Harmful practices such as FGM may be presented as integral cultural practices, but they may not be supported by everyone. Especially in patriarchal societies, it is highly unlikely women will challenge accepted cultural practices.<sup>31</sup>

### Right to education

Education is one of the social determinants of health and lack of education can limit the enjoyment of the right to health and other economic and social rights. Generally, lower levels of education are associated with poorer health outcomes, including illness, malnutrition, and higher rates of infant mortality. Therefore, it is important to consider access to education and quality education as part of the broader picture of health.

#### **Non-discrimination and equal access**

Minority populations experience unequal or restricted access to education as well as inappropriate education strategies.<sup>32</sup> Under international human rights law, governments have the obligation to ensure that “persons belonging to minorities have equal access to quality education leading to equal educational outcomes.”<sup>33</sup> To ensure equal access, governments should address all forms of discrimination against minorities. This includes, as CESCR explains, indirect discrimination which are laws or policies that may not be discriminatory at face value but have a disparate impact upon minorities.<sup>34</sup> For example, “requiring a birth registration certificate for school enrolment may discriminate against ethnic minorities or non-nationals who do not possess, or have been denied, such certificates.”<sup>35</sup>

30 Bakhru TS, *Reproductive rights: a long way to go* (2011) from Minority Rights Group International, *State of the World's Minorities and Indigenous Peoples 2011* (2011). [www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html](http://www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html).

31 Minority Rights Group International, *State of the World's Minorities and Indigenous Peoples 2011* (2011). [www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html](http://www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html).

32 UN Office of the High Commissioner for Human Rights, *United Nations Forum on Minority Issues: Compilation of Recommendations of the First Four Sessions 2008-2011*. [http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum\\_On\\_Minority\\_Pub\\_en\\_low.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum_On_Minority_Pub_en_low.pdf).

33 UN Human Rights Council, *Recommendations of the Forum on Minority Issues at its third session, on minorities and effective participation in economic life (14 and 15 December 2010)*, U.N. Doc. A/HRC/16/46 (Jan 31, 2011). <http://www2.ohchr.org/english/bodies/hrcouncil/docs/16session/A-HRC-16-46.pdf>.

34 UN Committee on Economic, Social and Cultural Rights, *General Comment No. 20, E/C.12/GC/20* (July 2, 2009).

35 *Ibid.* at para. 10 (b).

Many children from minority populations face discrimination both institutionally, such as being placed in a poorer quality school, or by teachers and students, such as by bullying. For example, the discriminatory education system in the Czech Republic barred Roma children from accessing quality education that would prepare them to be productive members of society. In the Czech Republic, Roma children were disproportionately placed in “practical” schools that provided sub-standard education rather than “standard” schools. In 2000, 19 Roma Czech nationals filed a case with the European Court for Human Rights claiming they were discriminated against on the basis of their race/ethnic origin in accessing education, and the Court found educational segregation discriminatory.<sup>36</sup> However, according to a February 2012 report from the Open Society Foundations, an estimated 20% of Roma children in the Czech Republic are still placed in “school designed for pupils with mild mental disabilities, compared to two percent of their non-Roma counterparts.”<sup>37</sup>

Exclusion and inequality in education are especially felt by minority and indigenous girls. A 2011 UNICEF report concludes that “Attendance and completion of secondary school is still largely beyond the reach of the poorest and most marginalized groups and communities in many countries. Girls, adolescents with disabilities and those from minority groups are especially disadvantaged.”<sup>38</sup>

For example, the MDG Report from Laos indicates that “compared with boys, girls from the Sino-Tibetan group [of minorities] are much less likely to be in school than those from the Lao-Tai group.” In China, girls from minority groups have experienced much lower rates of secondary school enrolment than Han girls, according to a 2010 article published by the World Bank.<sup>39</sup> Countries should pay special attention to the multiple forms of discrimination facing young minority girls.

### **Content and delivery of curriculum**

International human rights law demands that education for minorities, including curriculum and teaching methods, should be provided in a culturally appropriate manner and of good quality equal to national standards.<sup>40</sup> “Culturally appropriate” refers to restrictions or limitations that would limit a minority’s access to education. For example, the Committee on the Rights of the Child (CRC Committee) explains, “Discriminatory practices, such as restrictions on the use of cultural and traditional dress, should be avoided in the school setting.”<sup>41</sup> Likewise, The Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities (Declaration on Minorities), passed by the United Nations General Assembly, provides that “States shall take measures to create favourable conditions to enable persons belonging to minorities to express their characteristics and to develop their culture, language, religion, traditions and customs, except where specific practices are in violation of national law and contrary to international standards.”<sup>42</sup>

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- 36 D.H. and Others v. The Czech Republic, 57325/00 (Nov. 13, 2007). See also, Orsus and Others v. Croatia, 15766/03 (Mar. 16, 2010) (15 Roma children living in Orehovica, Podturen and Trnovec and born between 1988 and 1994, were required to attend segregated classes with only Roma pupils. The Court found that “the placement of the applicants in Roma-only classes at times during their primary education had no objective and reasonable justification” and therefore there was a violation article 14 prohibiting discrimination.).
- 37 Open Society Foundations, *Failing Another Generation: The Travesty of Roma Education in Czech Republic* (2012). [www.opensocietyfoundations.org/sites/default/files/failing-another-generation-20120601\\_o.pdf](http://www.opensocietyfoundations.org/sites/default/files/failing-another-generation-20120601_o.pdf). See also, Thomasen K, *A Hard Look at Discrimination in Education in Germany*, (Open Society Foundations, Oct. 17, 2012). [www.opensocietyfoundations.org/voices/hard-look-discrimination-education-germany](http://www.opensocietyfoundations.org/voices/hard-look-discrimination-education-germany).
- 38 UNICEF, *State of the World's Children 2011: Adolescence: An Age of Opportunity* (2011). [www.unicef.org/publications/files/SOWC\\_2011\\_Main\\_Report\\_EN\\_02242011.pdf](http://www.unicef.org/publications/files/SOWC_2011_Main_Report_EN_02242011.pdf), pg. 67.
- 39 Minority Rights Group International, *State of the World's Minorities and Indigenous Peoples 2011* (2011). [www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html](http://www.minorityrights.org/10848/state-of-the-worlds-minorities/state-of-the-worlds-minorities-and-indigenous-peoples-2011.html).
- 40 UN Committee on Economic Social and Cultural Rights, *General Comment No. 13*, E/C.12/1999/10 (Dec. 8, 1999).
- 41 Committee on the Rights of the Child (CRC), *General Comment No. 11*, U.N. Doc. CRC/C/GC/11 (Feb. 12, 2009).
- 42 UN General Assembly, *Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities*, U.N. Doc. A/RES/47/135 art. 4(2) (Dec 18, 1992). [www.un.org/documents/ga/res/47/a47r135.htm](http://www.un.org/documents/ga/res/47/a47r135.htm).

Educational instruction should be provided in minority languages whenever possible. The Declaration on Minorities explains that “States should take appropriate measures so that, wherever possible, persons belonging to minorities may have adequate opportunities to learn their mother tongue or to have instruction in their mother tongue.”<sup>43</sup> Many minorities speak two or more languages, which is important for their full participation in society. However, bilingualism can create difficulties and disadvantages in education—for example, if they are required to study in a language that is not their mother tongue.<sup>44</sup> The CESCR explains, “Discrimination on the basis of language or regional accent is often closely linked to unequal treatment on the basis of national or ethnic origin” and that it can hinder the enjoyment of many rights.<sup>45</sup> It also explains that “States parties should ensure that any language requirements relating to employment and education are based on reasonable and objective criteria.”<sup>46</sup>

Curricula that reflect minority cultures and history should also be provided.<sup>47</sup> The Declaration on Minorities explains that “States should, where appropriate, take measures in the field of education, in order to encourage knowledge of the history, traditions, language and culture of the minorities existing within their territory. Persons belonging to minorities should have adequate opportunities to gain knowledge of the society as a whole.”<sup>48</sup> The CRC elaborates on this obligation for indigenous peoples: “In order to effectively implement this obligation, States parties should ensure that the curricula, educational materials and history textbooks provide a fair, accurate and informative portrayal of the societies and cultures of indigenous peoples.”<sup>49</sup>

### Right to political participation

The CESCR identified political participation as an important aspect of the right to health in General Comment 14. CESCR writes that an “important aspect is the participation of the population in all health-related decision-making at the community, national and international levels.”<sup>50</sup> CESCR further explains:

*The formulation and implementation of national health strategies and plans of action should respect, inter alia, the principles of non-discrimination and people’s participation. In particular, the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12. Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people’s participation is secured by States.*<sup>51</sup>

International human rights law considers political and community participation as an important element of the right to health. Alicia Yamin writes that: “Realization of the right to health further implies providing

43 Ibid.

44 Izsák R, *Report of the independent expert on minority issues* U.N. Doc. A/HRC/19/56, (United Nations Human Rights Council, Jan. 3, 2012).

45 UN Committee on Economic Social and Cultural Rights, *General Comment No. 20*, U.N. Doc. E/C.12/GC/20 (July 2, 2009).

46 Ibid.

47 UN Office of the High Commissioner for Human Rights, *United Nations Forum on Minority Issues: Compilation of Recommendations of the First Four Sessions 2008-2011*. [http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum\\_On\\_Minority\\_Pub\\_en\\_low.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum_On_Minority_Pub_en_low.pdf).

48 UN General Assembly, *Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities*, U.N. Doc. A/RES/47/135 (Dec 18, 1992). [www.un.org/documents/ga/res/47/a47r135.htm](http://www.un.org/documents/ga/res/47/a47r135.htm), art. 4(4).

49 UN Committee on the Rights of the Child, *General Comment No. 11*, U.N. Doc. CRC/C/GC/11 (Feb. 12, 2009).

50 UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000), para. 11. See also para. 17: “A further important aspect is the improvement and furtherance of participation of the population in the provision of preventive and curative health services, such as the organization of the health sector, the insurance system and, in particular, participation in political decisions relating to the right to health taken at both the community and national levels”; and para. 34 “States should refrain from ... preventing people’s participation in health-related matters.”

51 Ibid. at para. 54.



individuals and communities with an authentic voice in decisions defining, determining, and affecting their well-being.”<sup>52</sup> Therefore, minority under-representation in public decision-making is an important element in understanding the structural determinants of minority health.

International human rights law explains that everyone has political rights, including the right to take part in government. The International Convention on the Elimination of Racial Discrimination (ICERD) explains that everyone, without distinction as to race, color, or national or ethnic origin, has political rights, including the right to vote in elections and to stand or elections, to take part in government, and to have equal access to public service.<sup>53</sup> However, minority populations are “almost always under-represented in national parliaments, in local governments, and in other areas of public life.”<sup>54</sup> Minorities face discrimination from effective [political] participation, which manifests itself in a range of ways including dissemination of information, civic advocacy and activism, and direct involvement in electoral politics.<sup>55</sup>

For example, in some countries, minorities are prevented from exercising their right to participate fully and effectively in public life in through electoral provisions. In Bosnia and Herzegovina, the country’s electoral provisions infringed upon the rights of minorities by preventing them from being candidates for the presidency and the House of the People solely on the ground of their race/ethnicity or religion. Two members of minorities, one Roma and one Jewish, against whom these provisions discriminated, brought the case to the European Court of Human Rights, which found that certain provisions of the Bosnian Constitution and election laws discriminated against minorities.<sup>56</sup>

The right to effective participation can be ensured through different means beyond equality in the electoral process, including “consultative mechanisms to special parliamentary arrangements and, where appropriate, may even include forms of territorial or personal autonomy.”<sup>57</sup> Alicia Yamin writes about the link between health and the construction of a functional democracy: “health-related resource distribution, evidence of discrimination and disparities, and the like are analyzed not just in terms of their impact on health status but also their relation to laws, policies, and practices that limit popular participation in decision-making and, in turn, the establishment of a genuinely democratic society.”<sup>58</sup>

## Rights of stateless and mobile populations

Lack of birth registration and identity documents presents a serious barrier for many minorities in accessing public services, including health care. For children born into minority or indigenous families living in remote areas, the risk of not being registered is even higher.<sup>59</sup> There are an estimated 15 million stateless persons in the world, and most belong to ethnic, religious, or linguistic minorities.<sup>60</sup> For example, in late 2001, more than half of all Roma in Serbia did not have a birth certificate or any document proving their citizenship. Almost one-third did not possess a health card.<sup>61</sup> The denial of birth registration or identity

52 Yamin AE, “The right to Health Under International Law and Its Relevance to the United States”. *American Journal of Public Health* 95 (July 2005): 7.

53 International Covenant on Economic, Social and Cultural Rights, art. 5(c). <http://www2.ohchr.org/english/law/cescr.htm>.

54 UN Office of the High Commissioner for Human Rights, *United Nations Forum on Minority Issues: Compilation of Recommendations of the First Four Sessions 2008-2011*. [http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum\\_On\\_Minority\\_Pub\\_en\\_low.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum_On_Minority_Pub_en_low.pdf).

55 Ibid.

56 Claridge L, *Discrimination and Political Participation in Bosnia and Herzegovina: Sejdic and Finci V. Bosnia and Herzegovina* (Minority Rights Group International, Mar. 12, 2010). [www.minorityrights.org/9773/briefing-papers/discrimination-and-political-participation-in-bosnia-and-herzegovina.html](http://www.minorityrights.org/9773/briefing-papers/discrimination-and-political-participation-in-bosnia-and-herzegovina.html).

57 UN Office for the High Commissioner for Human Rights, *United Nations Forum on Minority Issues: Compilation of Recommendations of the First Four Sessions 2008-2011*. [http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum\\_On\\_Minority\\_Pub\\_en\\_low.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/minority/docs/Forum_On_Minority_Pub_en_low.pdf).

58 Yamin AE, “The right to Health Under International Law and Its Relevance to the United States” *American Journal of Public Health* 95 (July 2005): 7.

59 World Health Organization, *Health of indigenous peoples* (Oct. 2007). [www.who.int/mediacentre/factsheets/fs326/en/index.html](http://www.who.int/mediacentre/factsheets/fs326/en/index.html).

60 UN Office of the High Commissioner for Human Rights, *Minority Rights: International Standards and Guidance for Implementation* (2010). [www.ohchr.org/Documents/Publications/MinorityRights\\_en.pdf](http://www.ohchr.org/Documents/Publications/MinorityRights_en.pdf).

61 Cameron L, ‘The Right to an Identity’. *Roma Rights Quarterly*. (European Roma Rights Centre, 2007). [www.errc.org/cikk.php?cikk=1066](http://www.errc.org/cikk.php?cikk=1066).



cards to minority groups is discriminatory and is contrary to international law.<sup>62</sup> While access to health care is only one factor shaping overall health, it is also critical to increasing social inclusion of minorities and ensuring equal opportunities for all.

### Rights of indigenous populations

Indigenous populations are unique with respect to their history, culture, ecology, geography, and politics. “As such, Indigenous Peoples have distinct status and specific needs relative to others. Indigenous Peoples’ unique status must therefore be considered separately from generalized or more universal social exclusion discussions.”<sup>63</sup> This resource does not adequately address the unique concerns of indigenous peoples, but rather introduces human rights concepts used in the area of indigenous peoples and health. It is recommended that the reader take note of this and pursue additional resources on indigenous rights. Resources are provided in Section 7 near the end of this chapter.

Indigenous people are often discriminated against or experience disparities in accessing health services and health outcomes. They are more likely to “suffer from poorer health, are more likely to experience disability and reduced quality of life and ultimately die younger than their non-indigenous counterparts.”<sup>64</sup> This inequality in health status of indigenous peoples “goes to the heart of the relationship between health and power, social participation, and empowerment.”<sup>65</sup>

In General Comment 14 on the right to health, CESCR dedicates a section to “identify elements that would help to define indigenous peoples’ right to health in order better to enable States with indigenous peoples to implement the provisions contained in Article 12 of the Covenant.”<sup>66</sup> CESCR explains that:

- Indigenous peoples have the right to specific measures to improve their access to health services and care.
- Health services should be culturally appropriate, taking into account traditional preventive care, healing practices and medicines.
- States should provide resources for indigenous peoples to design, deliver and control [health] services so that they may enjoy the highest attainable standard of physical and mental health.
- The vital medicinal plants, animals and minerals necessary to the full enjoyment of health of indigenous peoples should also be protected.

62 UN Office of the High Commissioner for Human Rights, *Minority Rights: International Standards and Guidance for Implementation* (2010). [www.ohchr.org/Documents/Publications/MinorityRights\\_en.pdf](http://www.ohchr.org/Documents/Publications/MinorityRights_en.pdf).

63 World Health Organization: Commission on the Social Determinants of Health, *Closing the gap in a generation: Health equity through action on the social determinants of health* (2008): 36. [http://whqlibdoc.who.int/publications/2008/9789241563703\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241563703_eng.pdf).

64 U.N. Department of Economic and Social Affairs, *State of the World's Indigenous Peoples* (2009). [www.un.org/esa/socdev/unpfii/documents/SOWIP\\_web.pdf](http://www.un.org/esa/socdev/unpfii/documents/SOWIP_web.pdf).

65 World Health Organization: Commission on the Social Determinants of Health, *Closing the gap in a generation: Health equity through action on the social determinants of health* (2008): 157. [http://whqlibdoc.who.int/publications/2008/9789241563703\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241563703_eng.pdf).

66 UN Committee on Economic, Social and Cultural Rights, *General Comment No. 14*, E/C.12/2000/4, para. 27 (Aug. 11, 2000),

## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO MINORITY HEALTH?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to minority health. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<b>UN treaty body interpretation</b> This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.
<b>Human rights standards</b>	<b>Case law</b> This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and minority health.

## Abbreviations

In the tables, we use the following abbreviations to refer to the fourteen treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
African Charter on the Rights and Welfare of the Child ( <b>ACRWC</b> )	African Committee of Experts on the Rights and Welfare of the Child ( <b>ACRWC Committee</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
Framework Convention for the Protection of National Minorities ( <b>FCNM</b> )	Committee of Ministers of the Council of Europe & Advisory Committee ( <b>AC</b> )
Convention concerning Indigenous and Tribal Peoples in Independent Countries ( <b>ILO Con</b> )	International Labour Organization ( <b>ILO</b> )

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**) including the United Nation Special Rapporteur on the situation of human rights and fundamental freedoms of indigenous people (**SR Indigenous**).

**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Non-discrimination and Equality	Art. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24
Expression & Information	Art. 19	Art. 19(2)			Art. 5(d) (viii)	Art. 12, Art. 13, Art. 17
Education	Art. 26		Art. 13	Art. 10	Art. 5(e) (v)	Art. 28, Art. 29
Participate in Public Policy	Art. 21	Art. 25		Art. 7	Art. 5(c)	
Bodily Integrity						

**Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Non-discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Expression & Information	Art. 9	Art. 10		Art. IV	Art. 13
Education	Art. 17			Art. XII	
Participate in Public Policy	Art. 13			Art. XX	Art. 23
Bodily Integrity					

**Table I: Minority Health and the Right to Non-Discrimination**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Housing policies force ethnic, minority communities into separate settlements that lack basic infrastructure and render inhabitants more vulnerable to illness and disease.</li> <li>• Ethnic minority members are more likely to be evicted from their homes and left to fend for themselves on the street.</li> <li>• Ethnic minority communities are expelled from their land and forced into settlements with inadequate facilities.</li> <li>• Hospitals place ethnic minority women in a separate maternity ward.</li> <li>• Denial of medical treatment, substandard care, or segregated care and treatment leading to severe pain and suffering for minorities.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 2(1):</b> Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</p>	<p><b>HRC:</b> Referring to ongoing discrimination faced by the Roma in almost all aspects of life covered by the ICCPR in <b>Slovakia</b> CCPR/C/SVK/CO/3 (HRC, 2011) and <b>Hungary</b> CCPR/CO/74/HUN (HRC, 2002), para. 7.</p>
<p><b>ICESCR 2(2):</b> The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status.</p> <p><b>ICESCR 3:</b> The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.</p>	<p><b>CESCR:</b> Recommending that <b>Moldova</b> “take urgent measures to ensure universal access to affordable primary health care, including by increasing the number of family doctors and community health centres, and include all members of society, including Roma, in the compulsory health insurance scheme. The committee also recommends that the state party take measures to ensure that emergency ambulance services are extended to Roma and older persons, without exception, and establish a special centre for the submission of complaints regarding the provision of such services.” E/C.12/MDA/CO/2 (CESCR, 2011)</p> <p><b>CESCR:</b> Noting persistent discrimination against the Roma in <b>Greece, Lithuania, and Serbia</b> in the fields of housing, health, employment, and education. E/C.12/1/ADD.97 (CESCR, 2004), para. 11; E/C.12/1/ADD.96 (CESCR, 2004), para. 9; e/c.12/1/ADD.108 (CESCR, 2005) para. 13.</p> <p><b>CESCR:</b> Noting that many Roma settlements in <b>Serbia</b> lack access to basic services such as electricity, running water, sewage facilities, medical care, and schools. E/C.12/1/ADD.108 (CESCR, 2005), para. 30.</p>

**Table I(cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 2(1):</b> States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.</p>	<p><b>CRC Committee:</b> Noting that children in Roma communities in <b>Greece</b> are exposed to substandard living conditions, including inadequate housing, poor sanitation and waste disposal, and no running water. CRC/C/15/ADD.170 (CRC, 2002), para. 64.</p> <p><b>CRC Committee:</b> Recommending that <b>Norway</b> “make every effort to ensure that children from ethnic minority backgrounds and indigenous children have equal access to all children’s rights, including access to welfare, health services and schools ...” CRC/C/NOR/CO/4 (CRC, 2010)</p> <p><b>CRC Committee:</b> Recommended that the <b>Philippines</b> “implement policies and programmes in order to ensure equal access for indigenous and minority children to culturally appropriate services, including social and health services and education.” CRC/C/PHL/CO/3-4 (CRC, 2009)</p>
<p><b>ICERD 2:</b> States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races.</p>	<p><b>CERD:</b> Recommending improving the health conditions of the Roma population: <b>Georgia</b> CERD/C/GEO/CO/4-5 (CERD, 2011); <b>Moldova</b> CERD/C/MDA/CO/8-9 (CERD, 2011); <b>Bosnia and Herzegovina</b> CERD/C/BIH/CO/7-8 (CERD, 2010); <b>Slovenia</b> CERD/C/SVN/CO/6-7 (CERD, 2010); <b>Slovakia</b> CERD/C/SVK/CO/6-8 (CERD, 2010); etc.</p> <p><b>CERD:</b> Recommending that the <b>Czech Republic</b> ensure that domestic legislation clearly prohibit racial discrimination in the enjoyment of the right to housing and protects the Roma from evictions. CERD/C/CZE/CO/7, March 2007.</p> <p><b>CERD:</b> Linking the critical health situation of Roma communities in <b>Lithuania</b> to their poor living conditions and recommending that the state address issues of drinking water supplies and sewage disposal systems in Roma settlements. CERD/C/LTU/CO/3 (CERD, 2006), para. 22.</p> <p><b>CERD:</b> Urging <b>Albania</b> “to fully implement all anti-discrimination policies that have been adopted with regard to the Roma minority in access to ... health. CERD/C/ALB/CO/5-8 (CERD, 2011).</p>
<p><b>CEDAW 2:</b> States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women.</p>	<p><b>CEDAW Committee:</b> Recommending that <b>Canada</b> “develop a specific and integrated plan for addressing the particular conditions affecting aboriginal women, both on and off reserves, and of ethnic and minority women, including poverty, poor health, inadequate housing, low school-completion rates, low employment rates, low income and high rates of violence.” CEDAW/C/CAN/CO/7 (CEDAW, 2008)</p> <p><b>CEDAW Committee:</b> Recommending that <b>Japan</b> “take effective measures, including the establishment of a policy framework and the adoption of temporary special measures, to eliminate discrimination against minority women.” CEDAW/C/JPN/CO/6 (CEDAW, 2009)</p> <p><b>CEDAW Committee:</b> Noting the multiple forms of discrimination faced by Roma women and girls in <b>Romania</b>, who remain marginalized with regard to their education, health, housing, employment, and participation in political and public life. CEDAW/C/ROM/CO/6 (CEDAW, 2006), para. 26.</p>

**Table I(cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 12(1):</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.</p> <p><b>CEDAW 12(2):</b> Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.</p>	<p><b>CEDAW Committee:</b> Explaining that “[s]tates parties are required by article 12 to take measures to ensure equal access to health care ... In some States there are traditional practices perpetuated by culture and tradition that are harmful to the health of women and children. These practices include dietary restrictions for pregnant women, preference for male children and female circumcision or genital mutilation.” General Recommendation No. 19 (11th Session, 1992), para. 19 -20.</p>

**Other Interpretations**

**International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, Art. 7.** States Parties undertake, in accordance with the international instruments concerning human rights, to respect and to ensure to all migrant workers and members of their families within their territory or subject to their jurisdiction the rights provided for in the present Convention without distinction of any kind.

**Framework Convention for the Protection of National Minorities (Europe)**

**European Charter, Art. 21(1).** Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age, or sexual orientation shall be prohibited. **Art 22.** The Union shall respect cultural, religious and linguistic diversity.

**Covenant on the Rights of the Child in Islam,** as adopted by the Organization of the Islamic Conference (OIC), Art. 15. The child [regardless of minority status] is entitled to physical and psychological care.

**Council of Europe: Convention on Biomedicine and Human Rights (Oviedo Convention) (1):** Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

**European Union Racial Equality Directive:** Council Directive 2000/43/EC of June 29, 2000, implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.



## Table 2: Minority Health and the Right to the Highest Attainable Standard of Health

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Doctors and health facilities are not located in or in close proximity to marginalized minority neighborhoods.</li> <li>• Ethnic minority patients are refused treatment, given inferior care, or abused in public health facilities.</li> <li>• Ethnic minority women lack access to maternal and reproductive health services.</li> <li>• Social policies disproportionately exclude ethnic minority individuals from access to health insurance.</li> <li>• Displaced from their lands, ethnic minority have been deprived of their traditional livelihood, and their health has suffered.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p> <p><b>ICESCR 12(2):</b> The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . <b>(c)</b> The prevention, treatment and control of epidemic, endemic, occupational and other diseases; <b>(d)</b> The creation of conditions which would assure to all medical service and medical attention in the event of sickness.</p>	<p><b>CESCR, General Comment 14:</b> Explaining that “States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds.” (para. 19)</p> <p><b>CESCR, General Comment 14:</b> Explaining that “[I]ndigenous peoples have the right to specific measures to improve their access to health services and care. . . . [D]evelopment-related activities that lead to the displacement of indigenous peoples against their will from traditional territories and environment, denying them their sources of nutrition and breaking their symbiotic relationship with their lands, has a deleterious effect on their health.” (para. 27)</p> <p><b>CESRC:</b> Recommending that <b>Israel</b> “ensure unrestricted access to health facilities, goods and services, including urgency treatment, for Palestinians living in the occupied <b>Palestinian territory</b> ... [and] to take disciplinary action against checkpoint officials who are found responsible for unattended roadside births, miscarriages, and maternal deaths resulting from delays at checkpoints, as well as maltreatment of Palestinian ambulance drivers.” Also recommending that “the state party should take urgent measures to ensure Palestinian women’s unrestricted access to adequate prenatal, natal and post-natal medical care [and] . . . to ensure the availability and accessibility of psychological trauma care for people living in Gaza, in particular children.” E/C.12/ISR/CO/3 (CESCR, 2011)</p> <p><b>CESCR:</b> Calling for the Roma’s inclusion in <b>Serbia</b>’s health insurance scheme. E/C.12/1/Add.108, June 2005, para. 60.</p>

**Table 2 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICERD 5:</b> State Parties undertake to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of . . . <b>(e)</b> . . . [t]he right to public health, medical care, social security and social services.</p>	<p><b>CERD:</b> Recommending that <b>Colombia</b>, in close consultation with the affected communities, devise a comprehensive strategy to guarantee that Afro-Colombians and indigenous peoples are provided with quality health care. Also explaining to <b>Colombia</b> that “CERD underlines the importance that targeted measures to improve the standard of living, including improved access to clean water and sewage systems, be linked to health indicators.” CERD/C/COL/CO/14 (CERD, 2009).</p> <p><b>CERD:</b> Recommending that the <b>United States</b> “continue efforts to address the persistent health disparities affecting persons belonging to racial, ethnic and national minorities, in particular by eliminating the obstacles that currently prevent or limit their access to adequate health-care, such as lack of health insurance, unequal distribution of health-care resources, persistent racial discrimination in the provision of health care and poor quality of public health-care services.” CERD/C/USA/CO/6 (CERD, 2008).</p> <p><b>CERD:</b> Recommending that the <b>United States</b> “pay particular attention to right to health and cultural rights of Western Shoshone people, which may be infringed upon by activities threatening their environment ...” CERD/C/USA/DEC/1 (CERD, 2006).</p> <p><b>CERD:</b> Recommending that <b>Estonia</b> “continue to implement programmes and projects in field of health, with particular attention to minorities, bearing in mind their disadvantaged situation.” CERD/C/EST/CO/7 (CERD, 2006).</p> <p><b>CERD:</b> Encouraging the implementation of programs to improve Roma health in <b>Lithuania</b>, bearing in mind their disadvantaged situation resulting from extreme poverty and low levels of education. CERD/C/LTU/CO/3, para. 22 (2006).</p> <p><b>CERD:</b> Recommending that <b>Guatemala</b>, “in close consultation with the communities concerned, devise a comprehensive and culturally appropriate strategy to guarantee that indigenous peoples are provided with quality health care” and that “the implementation of such a strategy should be ensured by providing adequate resource allocations, in particular for the indigenous peoples and intercultural health unit, together with the active participation of departmental and municipal authorities, compilation of appropriate indicators and transparent progress monitoring “ and that “particular attention should be paid to improving access to health care for indigenous women and children.” CERD/C/GTM/CO/12-13 (CERD, 2010).</p> <p><b>CERD:</b> Calling on <b>Romania</b> to guarantee access by Roma to health care and services, and also to social services, and continue to support Roma health mediators. CERD/C/ROU/CO/16-19 (CERD, 2010).</p> <p><b>CERD:</b> Finding that, in the <b>United States</b>, wide racial disparities continue to exist in sexual and reproductive health, particularly with regard to the high maternal and infant mortality rates among women and children belonging to racial, ethnic and national minorities, especially African Americans; the high incidence of unintended pregnancies and greater abortion rates affecting African American women; and the growing disparities in HIV infection rates for minority women. CERD/C/USA/CO/6 (2008).</p> <p><b>CERD:</b> Urging <b>Norway</b> to “take measures to address the discrimination [of non-citizens] including with regard to access to ... health, including the provision of specialized mental and physical health services for traumatized refugees and asylum-seekers.” CERD/C/NOR/CO/19-20 (CERD, 2011).</p> <p><b>CERD:</b> Recommending that <b>India</b> “ensure equal access to ration shops, adequate health care facilities, reproductive health services, and safe drinking water for members of scheduled castes and scheduled and other tribes and to increase the number of doctors and of functioning and properly equipped primary health centres and health sub-centres in tribal and rural areas.” CERD/C/IND/CO/19 (CERD, 2007).</p>

**Table 2 (cont.)**

Human Rights Standards	Treaty Body Interpretation
	<p><b>CERD:</b> recommending that <b>Panama</b> “ensure that sexual and reproductive health services are available for and accessible to the whole population, and in particular the Kuna community. CERD/C/PAN/CO/15-20 (CERD, 2010).</p> <p><b>CERD:</b> Recommending that <b>Chile</b> take measures “to integrate the traditional medicine of indigenous peoples in the state party’s health-care system.” CERD/C/CHL/CO/15-18 (CERD, 2009).</p> <p><b>CERD:</b> Recommending that <b>Slovakia</b> “act firmly against local measures denying residence to Roma and the unlawful expulsion of Roma, and refrain from placing Roma in camps outside populated areas that are isolated and without access to health care and other basic facilities.” CERD/C/SVK/CO/6-8 (CERD, 2010).</p> <p><b>CERD:</b> Recommending that <b>Mozambique</b> “strengthen its programmes aimed at providing universal access to health care, with particular attention to members of vulnerable groups, including non-citizens and persons without any identification documents, and encourages the state party to take further measures to prevent and combat HIV/AIDS, malaria and cholera.” A/62/18 (CERD, 2007).</p> <p><b>CERD:</b> Recommending to <b>Mexico</b> that it “draw up, in close cooperation with the communities concerned, a comprehensive and culturally sensitive strategy to ensure that indigenous peoples receive quality health care. The implementation of the strategy should be guaranteed by an adequate allocation of resources, the collection of indicators and transparent monitoring of progress. Particular attention should be paid to improving access to health care for indigenous women and children. The committee underlines the need for interpreters in this area too, in order to ensure that indigenous people have full access to health services. It is important that the health system recognize, coordinate, support and strengthen indigenous health systems and use them as the basis for achieving more effective and culturally sensitive coverage. The committee requests the state party to provide clear data on maternal mortality and life expectancy in indigenous communities and among people of African descent. Lastly, the committee recommends that the state party step up its efforts to improve the sexual and reproductive health of indigenous women and women of African descent. CERD/C/MEX/CO/16-17 (CERD, 2012).</p>
<p><b>CEDAW 12(1):</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health services, including those related to family planning.</p>	<p><b>CEDAW Committee:</b> Noting the Roma women’s marginalization and lack of access to health care and calling upon <b>Macedonia</b> to provide information on concrete projects to address these problems. CEDAW/C/MKD/CO/3, Feb 2006, para. 28.</p>
<p><b>CRC 24(1):</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.</p>	<p><b>CRC Committee:</b> Noting the limited access to health services for Roma children in <b>Hungary</b>. CRC/C/HUN/CO/2 (CRC, 2006), para. 41.</p>

**Table 2 (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 2:</b> Right to life (which, of course, necessarily includes the human right to health).</p>	<p><b>ECtHR:</b> “The Court reiterates that the first sentence of Article 2 § 1 enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction . . . the State’s positive obligation under Article 2 has also been found to be engaged in the health care sector, be it public or private, as regards the acts or omissions of health professionals . . . .” <i>Ilbeyi Kemaloglu and Meriye Kemaloglu v. Turkey</i>, 19986/06 (April 10, 2012), para. 32-34.</p>

**Other Interpretations**

**SR Indigenous Peoples:** Recommending that **South African** social services, health, and education departments give high priority attention to San needs and grievances. [E/CN.4/2006/78/Add.2 (SR Indigenous, 2005), para. 92].

**SR Indigenous Peoples:** Recommending that the **Democratic Republic of Congo** strengthen efforts to ensure that indigenous peoples have equal access to primary health care and that the basic health needs of indigenous communities are met, especially in remote areas. A/HRC/18/35/Add.5 (2011).

**SR Indigenous Peoples:** Recommending that **Colombia**, in collaboration with indigenous authorities and organizations, make a concerted effort to reduce the high levels of mortality and morbidity in their communities, in particular, health centres with medical staff should be established within indigenous territories, in order that care may be provided promptly – especially to the many communities in remote areas; urging the State to develop and implement a strategy for the prevention of death caused by malnutrition among children, pregnant women and the elderly in indigenous communities. A/HRC/15/37/ADD.3 (2010).

**SR Racism:** Recommending to **Brazil**, with regard to indigenous communities, that the “concerning system of provision of health care be revised in consultation with Indian communities, in light of inefficiency.” E/CN.4/2006/16/Add.3 (SR Racism, 2006).

**Council of Europe: Convention on Biomedicine and Human Rights (Oviedo Convention) (3):** Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.

**European Charter of Fundamental Rights (35):** Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices.

**European Race Equality Directive (1):** The purpose of this Directive is to lay down a framework for combating discrimination on the grounds of racial or ethnic origin, with a view to putting into effect in the Member States the principle of equal treatment. (3)(1): Within the limits of the powers conferred upon the Community, this Directive shall apply to all persons, as regards both the public and private sectors, including public bodies, in relation to: (e) social protection, including social security and healthcare.

**Table 3: Minority Health and the Right to Expression and Information**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• There are fewer health facilities in ethnic minority communities, and there is little attempt to provide them with basic health information.</li> <li>• Ethnic minority women lack access to information on sexual and reproductive health.</li> <li>• Data on minorities' health is inadequate, hindering the development of policies to address the needs of these communities.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR General Comment No. 14 (12):</b> Health care accessibility “includes the right to seek, receive and impart information and ideas concerning health issues.”</p>
<p><b>CEDAW 10(h):</b> Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning.</p> <p><b>CEDAW 16(1)(e):</b> The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.</p>	<p><b>CEDAW Committee:</b> Noting the lack of information on Roma women and their access to health services in <b>Hungary</b>; recommending data collection disaggregated by sex and the implementation of health awareness campaigns. A/57/38(SUPP), Aug 2002, para. 332.</p> <p><b>CEDAW Committee:</b> Urging the collection of statistical information on the health of Roma women and girls in <b>Romania</b> in order to develop policies responsive to their needs. CEDAW/C/ROM/CO/6 (CEDAW 2006) para. 27.</p>
<p><b>FCNM 9(1):</b> The Parties undertake to recognize that the right to freedom of expression of every person belonging to a national minority includes freedom to hold opinions and to receive and impart information and ideas in the minority language.</p>	<p><b>AC:</b> Highlighting the need for data to assess Roma (and particularly Roma women’s) access to health services and education in <b>Slovakia</b>; data would have to be provided voluntarily, and Roma communities should be informed about the methods and purpose of data collection. ACFC/OP/II(2005)004, May 2005, para. 11.</p>

**Table 4: Minority Health and the Right to Education**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Due to poor educational facilities in ethnic minority communities, illiteracy rates are high, and children are unable to access important health information.</li> <li>Ethnic minority children are channelled into “special schools,” which provide an inferior education and limit their access to health information.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 19(2):</b> Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.</p>	<p><b>HRC:</b> Noting the “grossly disproportionate” number of Roma children assigned to special schools and urging <b>Slovakia</b> to take immediate steps to eradicate this segregation. CCPR/CO/78/SVK (HRC, 2003), para. 18.</p>
<p><b>ICESCR 13(1):</b> The State Parties . . . recognize the right of everyone to education. . . . [E]ducation shall be directed to the full development of the human personality and the sense of its dignity.</p>	<p><b>CESCR:</b> Urging the elimination of discrimination against Roma children in the <b>Czech Republic</b> by removing them from special schools and integrating them into the mainstream educational system. E/C.12/1/ADD.76 (CESCR, 2002), para. 44.</p>
<p><b>ICERD 5:</b> In compliance with the fundamental obligations laid down in article 2 of this Convention, States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights: <b>(d)(v)</b> The right to education and training.</p>	<p><b>CERD:</b> Calling upon the <b>Czech Republic</b> to promptly eradicate racial segregation and the placement of a disproportionate number of Roma children in special schools. CERD/C/304/ADD.109 (CERD, 2001), para. 10.</p> <p><b>CERD:</b> noting that cultural and linguistic rights of the San are not fully respected in educational curricula in <b>Botswana</b>. A/57/18(Supp) (CERD, 2001), para. 305.</p>
<p><b>CRC 28:</b> States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity,</p>	<p><b>CRC Committee:</b> Calling upon <b>Moldova, Poland,</b> and the <b>Ukraine</b> to develop and implement a plan aimed at integrating all Roma children into mainstream education and prohibiting their segregation into special classes. CRC/C/15/ADD.191 (CRC, 2002), para. 75; CRC/C/15/ADD.194 (CRC, 2002), para. 53; CRC/C/15/ADD.192 (CRC, 2002), para. 50.</p> <p><b>CRC Committee:</b> urging <b>South Africa</b> to guarantee the rights of San children, particularly concerning language and access to information. CRC/C/15/ADD.122 (CRC, 2000), para. 41.</p>

**Other Interpretations**

**European Charter of Fundamental Rights** (14) (1): Everyone has the right to education and to have access to vocational and continuing training. (2) This right includes the possibility to receive free compulsory education.

**European Race Equality Directive** (1): The purpose of this Directive is to lay down a framework for combating discrimination on the grounds of racial or ethnic origin, with a view to putting into effect in the Member States the principle of equal treatment. (3)(1): Within the limits of the powers conferred upon the Community, this Directive shall apply to all persons, as regards both the public and private sectors, including public bodies, in relation to: (g) education.

**Table 5: Minority Health and the Right to Participate in Public Life**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Ethnic minority members are unable to obtain citizenship papers and a health card, leaving them without access to social and health services.</li> <li>• Labelled “child-like,” ethnic minority members have little say in policy decisions affecting their health and well-being.</li> <li>• Ethnic minorities, particularly women, are unable to participate in public life and access needed social services.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 25:</b> Every citizen shall have the right and the opportunity, without . . . distinctions . . . (a) To take part in the conduct of public affairs, directly or through freely chosen representatives.</p>	<p><b>HRC:</b> Recommending that <b>France</b> “[f]acilitate the participation of persons who are members of minority groups in publicly elected bodies, including the national assembly and local government. In particular, seek ways to increase the number of candidates belonging to minorities included in the list of political parties running for elections. The appointment of persons from minority backgrounds as members of the police, public administration and the judiciary, is also important to assure the representation of the needs of varied communities in the planning, design, implementation and evaluation of policies and programmes affecting them.” CCPR/C/FRA/CO/4 (HRC, 2008).</p>
<p><b>ICCPR 26:</b> All persons are equal before the law and are entitled without any discrimination to the equal protection of the law.</p>	<p><b>HRC:</b> Calling for the removal of all administrative obstacles and fees to enable the Roma in <b>Bosnia</b> to obtain personal documents necessary for them to access health insurance and other basic rights. CCPR/C/BIH/CO/1 (HRC, 2006), para. 22.</p>
<p><b>ICERD 5(c):</b> States will guarantee political rights, in particular the right to take part in the Government as well as in the conduct of public affairs at any level and to have equal access to public services.</p>	<p><b>CERD:</b> Recommending that <b>Paraguay</b> take the necessary steps to register all children in its territory, particularly those residing in areas inhabited by indigenous peoples, while safeguarding and respecting their culture, and ensure that they receive the services required to promote their intellectual and physical development. CERD/C/PRY/CO/1-3 (CERD, 2011).</p> <p><b>CERD:</b> Indicating that the Roma Council in <b>Bosnia</b> does not have sufficient funding or resources to fulfill its mandate and is rarely consulted by the Council of Ministers. [CERD/C/BIH/CO/6 (CERD, 2006), para. 14.</p> <p><b>CERD:</b> Noting the cultural, social, economic, and political exclusion of San peoples in <b>Botswana</b>. CERD/A/57/Supp.18 (CERD, 2001), para. 301.</p>
<p><b>ICERD 5:</b> In compliance with the fundamental obligations laid down in article 2 of this Convention, States Parties undertake to prohibit and to eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights: (a) the right to equal treatment before the tribunals ... (d)(iii) The right to housing; (d)(iv) The right to public health, medical care, social security and social services; (d)(v) The right to education and training.</p>	<p><b>CERD:</b> Expressing concern that a lack of identification documents effectively deprives the Roma in the <b>Ukraine</b> of their right to equal access to health care, housing, social security, education, and the legal system. CERD/C/UKR/CO, August 2006, para. 11.</p>



**Table 5 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<b>ICESCR 12(1):</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	<b>CESCR, General Comment 14:</b> Explaining the importance of “participation in political decisions relating to the right to health taken at both the community and national levels.” [para. 17].
<b>CEDAW 7:</b> State Parties shall take all appropriate measures to eliminate discrimination against women in the political and public life of the country and, in particular, shall ensure to women, on equal terms with men, the right: . . . (b) [t]o participate in the formulation of government policy and the implementation thereof.	<b>CEDAW Committee:</b> Calling for the immediate issuance of identity documents to Roma women in <b>Romania</b> . CEDAW/C/ROM/CO/6 (CEDAW 2006) para. 27.
<b>FCNM 15:</b> The Parties shall create the conditions necessary for the effective participation of persons belonging to national minorities in cultural, social and economic life and in public affairs, in particular those affecting them.	<b>AC:</b> Noting the “weak and ineffective participation by the Roma community” in design and implementation of health strategies in <b>Romania</b> . ACFC/OP/II(2005)007, Nov 2005, para. 540.

Human Rights Standards	Case Law
<p><b>African Children’s Charter 14 (1):</b> Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health.</p> <p><b>(2)</b> State Parties to the present Charter shall undertake to pursue the full implementation of this right:</p> <p><b>(b)</b> to ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;</p> <p><b>(c)</b> to ensure the provision of adequate nutrition and safe drinking water;</p> <p><b>(g)</b> to integrate basic health service programmes in national development plans.</p>	<p><b>ACHPR (Committee):</b> The Committee held that Kenya violated the right to health of children of Nubian descent under the African Children’s Charter, stating that “[t]here is de facto inequality in their access to available health care resources, and this can be attributed in practice to their lack of confirmed status as nationals of the Republic of <b>Kenya</b>. Their communities have been provided with fewer facilities and a disproportionately lower share of available resources as their claims to permanence in the country have resulted in health care services in the communities in which they live being systematically overlooked over an extended period of time.” 002/09: <i>IHRDA and Open Society Justice Initiative (OSJI)</i> (on behalf of children of Nubian descent in Kenya) <i>v. Kenya</i>.</p>
<p><b>ESC 12 Part I:</b> Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable.</p> <p><b>Part II:</b> With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in cooperation with public or private organisations, to take appropriate measures designed inter alia:</p> <ol style="list-style-type: none"> <li>1. to remove as far as possible the causes of ill-health;</li> <li>2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;</li> <li>3. to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.</li> </ol>	<p><b>ECSCR:</b> The Commission held that <b>Bulgaria</b> violated the right to health by not granting about 46% of the Roma population state-subsidized health insurance. Under the current law, many Roma cannot access health insurance because it is made conditional on being eligible for the right to social assistance or being registered as unemployed. <i>European Roma Rights Centre (ERRC) v. Bulgaria</i>, Complaint No. 46/2007(2008).</p>

## Table 5 (cont.)

### Other Interpretations

**SR on the rights of Indigenous People:** Stating to the **Congo** that “[i]t is essential, as part of this process, to include indigenous peoples themselves in the design and delivery of culturally appropriate projects, especially in areas of poverty reduction, health and education.” A/HRC/18/35/Add.5 (SR Indigenous, 2011)

**SR on the rights of Indigenous People:** Highlighting that the San are not sufficiently empowered to impact government decisions regarding allocation of limited resources in **South Africa**. E/CN.4/2006/78/Add.2 (SR Indigenous, 2005), para. 75.

**Independent Expert on Minority Issues:** Recommending to **Bulgaria**, “The small, inconsistent pilot-project-based approach that has characterized government activities to date will never reach the transformative tipping point necessary to confront the vast socio-economic challenges faced by the Roma. A new, holistic and incisive approach to Roma integration, designed and implemented in full consultation with Roma organizations, is required to break the vicious circle of social exclusion and poverty. Furthermore, Roma themselves must make efforts to engage fully with government initiatives, not as passive recipients, but as pro-active stakeholders in immediate and longer-term Roma integration strategies. It is essential that Roma have a role in decision - making and are fully consulted in decisions that affect them.” A/HRC/19/56/Add.2 (IE Minorities, 2012)

**Independent Expert on Minority Issues:** Noting of **Kazakhstan** that “groups, including Roma and Luli (or Lyuli), were generally described as nomadic or itinerant and with livelihoods solely in the informal sector [and that] such groups are not represented in the assembly of the people or other state institutions [and] they often lack identification documents required to secure services and may be vulnerable with regard to access to healthcare, education, housing and the effects of extreme poverty.” A/HRC/13/23/Add.1 (IE Minorities, 2010)

**Special Rapporteur on the highest attainable level of health:** recommending that **Guatemala** “[i]ncorporate and ensure the consultation and participation of indigenous community members in the development of policies and programmes related to the delivery of health services and goods into indigenous communities.” A/HRC/17/25/ADD.2 (SR Health, 2011)

**European Race Equality Directive Preamble (12):** To ensure the development of democratic and tolerant societies which allow the participation of all persons irrespective of racial or ethnic origin, specific action in the field of discrimination based on racial or ethnic origin should go beyond access to employed and self-employed activities and cover areas such as education, social protection including social security and healthcare, social advantages and access to and supply of goods and services.

**Table 6: Minority Health and the Right to Bodily Integrity**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Ethnic minority children are disproportionately targeted by police officers and subjected to ill-treatment and abuse.</li> <li>• Ethnic minority women are coercively sterilized without their fully informed consent.</li> <li>• Ethnic minority women and children are frequent victims of domestic violence due to extreme living conditions such as land dispossession, community isolation, high unemployment, poverty, and alcohol abuse.</li> <li>• Due to discriminatory attitudes, police are especially reluctant to interfere when ethnic minority women are victims of domestic violence.</li> </ul>

**Note:** The right to bodily integrity is not specifically recognized under the ICCPR, ICESCR, or European conventions, but has been interpreted to be part of the right to security of the person (ICCPR 9, ECHR 5), the right to freedom from torture and cruel, inhuman, and degrading treatment (ICCPR 7, ECHR 3), and the right to the highest attainable standard of health (ICESCR 12, ESC 11). The CESCR remarked that a “major goal” under the right to health should be “protecting women from domestic violence.” [CESCR GC 14, para. 21]. Although CEDAW does not specifically address bodily integrity, the CEDAW Committee indicated that the “definition of discrimination includes gender-based violence.” CEDAW Committee, General Rec. 19, paras 6-7.

Human Rights Standards	Treaty Body Interpretation
<p><b>ICERD 5:</b> State Parties undertake to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of . . .</p> <p><b>(b)</b> [t]he right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution.</p>	<p><b>CERD:</b> Recommending that <b>Slovakia</b> “establish clear guidelines concerning the requirement of ‘informed consent’ and to ensure that these guidelines are well-known among practitioners and the public, in particular Roma women [and] that all reports of sterilization without informed consent be duly acknowledged and that victims be provided with adequate remedies, including apologies, compensation and restoration, if possible.” CERD/C/SVK/CO/6-8 (CERD, 2010) This problem also noted by the <b>HRC</b> CCPR/C/SVK/CO/3 (HRC, 2011) and <b>Committee Against Torture</b> CAT/C/SVK/CO/2 (CAT, 2009).</p> <p><b>CERD:</b> Remarking on police brutality against the Roma in the <b>Ukraine</b>, including arbitrary arrests and illegal detention. A/56/18(SUPP) (CERD, 2001), para. 373.</p> <p><b>CERD:</b> Noting that Roma members, especially the young, in <b>Albania</b> are subjected to ill-treatment and improper use of force by police officers. CERD/C/63/CO/1 (CERD, 2003), para. 18.</p>
<p>Although CEDAW does not specifically address bodily integrity, the CEDAW Committee indicated that the “definition of discrimination includes gender-based violence.” [CEDAW Committee, General Rec. 19, paras 6-7].</p>	<p><b>CEDAW Committee:</b> recommending that <b>China</b> “investigate and prosecute reports of abuse and violence against ethnic minority women by local family planning officials, including forced sterilization and forced abortion.” CEDAW/C/CHN/CO/6 (CEDAW, 2006)</p> <p><b>CEDAW Committee:</b> noting the continuing gender-based discrimination and violence that Roma women face in their own communities in <b>Sweden</b>. A/56/38(SUPP) (CEDAW, 2000), para. 356.</p> <p><b>CEDAW Committee:</b> calling upon the <b>Czech Republic</b> to provide redress to Roma women victimized by coercive sterilization and to prevent further involuntary sterilizations. CEDAW/C/CZE/CO/3 (CEDAW, 2006), para. 24.</p>

**Table 6 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 19(1):</b> States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.</p>	<p><b>CRC Committee:</b> Recommending that the <b>Syrian Arab Republic</b> “address the issue of temporary marriages, including by raising awareness among children, families and within the community of the negative impact of such marriages on the physical and mental health and general well-being of girls, and ensure that legal proceedings are engaged against those who organize those marriages.” CRC/C/SYR/CO/3-4 (CRC, 2012)</p> <p><b>CRC Committee:</b> Observing continued allegations of ill-treatment and torture by the police of Roma children in the <b>Ukraine</b> and urging investigation. CRC/C/15/ADD.191 (CRC, 2002), para. 36.</p>
<p><b>FCNM 6(1):</b> The parties undertake to take appropriate measure to protect persons who may be subject to threats or acts of discrimination, hostility or violence as a result of their ethnic, cultural, linguistic or religious identity.</p>	<p><b>AC:</b> Pointing to cases of abusive behavior, hostile attitudes, and violence by police against Roma members in <b>Romania</b>. ACFC/OP/II(2005)007, November 2005.</p>
<p>The right to bodily integrity is not specifically recognized under the ICCPR, but has been interpreted to be part of the right to security of the person in <b>ICCPR 9</b>, and the right to freedom from torture and cruel, inhuman, and degrading treatment in <b>ICCPR 7</b>.</p>	<p><b>HRC:</b> Concluding that “Roma and other women have been subjected to sterilization without their consent” and recommending that the <b>Czech Republic</b> “ensure fully informed consent in all proposed cases of sterilization and take the necessary measures to prevent involuntary or coercive sterilization in the future, including written consent forms printed in the Roma language, and explanation of the nature of the proposed medical procedure by a person competent in the patient’s language” CCPR/C/CZE/CO/2 (HRC, 2007).</p>

Human Rights Standards	Case Law
<p><b>ECHR 8(1):</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><b>ECHR 8(2):</b> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p><b>ECtHR:</b> “The applicant [a Roma patient] complained that her right to respect for her private and family life had been violated as a result of her sterilisation without her full and informed consent.” The Court found that there was a violation of Art. 8. Case of <i>V.C. v. Slovakia</i>, 18968/07 (November 8, 2011).</p> <p><b>ECtHR:</b> NB was sterilized while undergoing a caesarean section at a public hospital. However, NB was only 17 years old at the time of the intervention, so she was also legally a minor. The hospital, in addition to having NB sign the consent form after the administration of tranquilizing premedication, never obtained the consent of her legal guardians. NB did not learn of her sterilization until several months after the fact because it was not noted in her release report from the hospital. The Court unanimously held that NB had been sterilized without informed consent and in contravention of Articles 8 and 13. <i>N.B. v. Slovakia</i>, 29518/10 (June 12, 2012).</p>

### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>67</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>68</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>69</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>70</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>67</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>68</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>69</sup> Ibid.

<sup>70</sup> Ibid.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>71</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

<sup>71</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.



## **4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF MINORITY HEALTH?**

This section contains five examples of effective human rights-based work addressing health and human rights in minority communities. These are:

1. Justice for Roma women coercively sterilized in Central Europe
2. Promoting the rights of Roma patients in the Macedonian healthcare system
3. Ending discrimination in access to nationality for children of Nubian descent in Kenya
4. Roma health mediators in Romania
5. Campaign for indigenous health equality in Australia

## Example I: Justice for Roma women coercively sterilized in Central Europe

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### Project Type

Advocacy/Litigation

### Organization

The European Roma Rights Centre (A Roma Legal Advocacy Organization), Life Together (a Roma-Czech CBO), the League of Human Rights (a Czech NGO), the Group of Women Harmed by Forced Sterilization (a victims advocacy group), the Peacework Development Fund, the Counseling Center for Citizenship, Civil and Human Rights (a Czech NGO) and the Center for Reproductive Rights (a global legal advocacy organization) have worked together on litigation and advocacy campaigns in the Czech Republic, Hungary, and Slovakia to secure public recognition and compensation for harms suffered by Roma women who were coercively sterilized.

### Problem

From the 1970s until 1990, the Czechoslovak government coercively sterilized Roma women, programmatically aiming to reduce their “high, unhealthy” birth rates. Forced sterilization has been documented as late as 2004 in the Czech Republic. Cases have also reportedly occurred in Hungary, Romania, Bulgaria, and Slovakia. Hundreds of Roma women await justice.

### Actions Taken

- In 2003, the Center for Reproductive Rights (CRR) and the Slovak Counseling Center published “Body and Soul,” a report on coercive and forced sterilizations of Romani women in Slovakia. In 2004, The European Roma Rights Center (ERRC), and Life Together, along with other local NGOs, documented cases of coercive sterilization and filed complaints with the Ombudsman—the Czech Public Defender of Rights.
- In 2005, Roma women established an advocacy group in the Czech Republic for victims, the Group of Women Harmed by Forced Sterilisation (GWHFS), to push the government and medical authorities for a formal apology and to establish a compensation fund.
- GWHFS used demonstrations and awareness campaigns, and in 2006, a member testified before the UN Committee on the Elimination of Discrimination against Women (CEDAW).
- In July 2011, the ERRC submitted a report to the UN Committee on the Elimination of Racial Discrimination (CERD), *inter alia*, advocating for the elimination of the three-year statute of limitation for involuntary sterilization claims in the Czech Republic and proposing that the Czech Government distribute the FIGO Guidelines on female sterilization to health service providers throughout the country (guidelines available at: [www.figo.org/files/figo-corp/FIGO%20-%20Female%20contraceptive%20sterilization.pdf](http://www.figo.org/files/figo-corp/FIGO%20-%20Female%20contraceptive%20sterilization.pdf)).
- ERRC filed a parallel report to the Universal Periodic Review on the Czech Republic in 2012. The report described the experience of Czech women of Roma origin with respect to involuntary sterilization and recommended that the Czech Government take various measures to comply with its international human rights obligations.

- ERRC, with the support of the Roma Health Project Health Program and OSF, represented a Hungarian woman of Roma origin in a civil action for damages on civil rights and negligence claims. ERRC argued their client's sterilization occurred without full and informed consent. The domestic court of appeal ruled that since sterilizations are reversible no damages were due to ERRC's client. This ruling is based on incorrect medical expert testimony. Therefore, after having exhausted domestic remedies, ERRC brought their client's case to the UN Committee for the Elimination of Discrimination against Women under its Optional Protocol, where the committee found multiple violations of the Convention on the Elimination of Discrimination Against Women and entered judgment for ERRC's client, who was eventually compensated.

### Results and Lessons Learned

- In 2005, the Ombudsman undertook an investigation and published a report recognizing coercive sterilization and racial targeting in the Czech medical and social work community. The report recommended changes in domestic law to ensure informed consent and the simplification of compensation procedures.
- The Ombudsman also filed 54 criminal complaints with the local prosecuting office, but many have been dismissed.
- The 2006 CEDAW report to the Czech government expressed concern over cases of coercive sterilization and recommended the adoption of legislative changes to ensure informed consent and victim compensation.
- In 2006, in *A.S. v. Hungary*, CEDAW found Hungary in violation and likewise called for informed consent and compensation legislation. This marks the first time an international human rights tribunal has held a government accountable for failing to provide necessary information to a woman to enable her to give informed consent to a reproductive health-related medical procedure.
- In 2009, the Czech Prime Minister apologized to the country's victims of coercive sterilization .
- The Czech Government is further along in acknowledging its wrongdoings, while the Slovak government has strenuously rejected all allegations made concerning these cases over the last ten years. Slovak government officials have recently called for re-incentivizing sterilization of Romani women in Slovakia .
- In 2011, the International Federation of Obstetrics and Gynecology revised and updated its ethical guidelines on the performance of female sterilization in light of these cases and developments.
- In 2012, the Czech Human Rights Council passed a decision urging the Czech government to introduce a compensation mechanism for all victims of involuntary sterilization.
- On November 13, 2012, the European Court of Human Rights issued its latest judgment in a series of cases dealing with the involuntary sterilization of Roma women in Slovakia. The court unanimously found that two applicants were the victims of coerced sterilization in violation of Article 3 (prohibition of inhuman or degrading treatment) and Article 8 (right to respect for private and family life) of the European Convention on Human Rights. The European Court of Human Rights has issued three decisions finding Slovakia in violation of reproductive rights of Romani women due to their forced and sterilization: *V.C. v. Slovakia* [2011], *N.B. v. Slovakia* [2012], and *I.G. and Others v. Slovakia* [2012].
- In 2013, the UN Special Rapporteur on Torture included the issue of forced sterilization in his report on torture in health care.

## Minority Health

- International treaties and standards were critical to the litigation to complement the lack of medical experts in Hungary and Czech Republic willing to testify that sterilization is irreversible and the lack of domestic support for such litigation in general.
- Patients whose rights have been violated are the best advocates for change. Collaborations between legal service providers, patient advocates, and Roma activists brought attention to the matter and helped address larger issues.

### **European Roma Rights Centre**

Budapest, Hungary

Email: [office@errc.org](mailto:office@errc.org)

Web: [www.errc.org](http://www.errc.org)

## Example 2: Promoting the rights of Roma patients in the Macedonian health care system

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### Project

Advocacy

### Actor/Organization

The Association for Emancipation, Solidarity and Equality of Women (ESE) in Macedonia promotes women's human rights and social justice in Macedonia. The ESE paralegal project is supported by the Roma Health Project and the Law and Health Initiative by the Public Health Program at Open Society Foundation. ESE works closely with three Roma human rights groups: (1) the Centre for Democratic Development and Initiatives (CDRIM), which works on democratization and human rights, education, and health for the Roma Community living in Sutro Orizari; (2) the Humanitarian and Charitable Association of Roma (KHAM), which is a Delveco communication organization that aims to improve the social, economic, health and education level of the Roma community; (3) and the Roma Resource Center (RCC), which is focused on social inclusion of marginalized groups, gender equality and transparency in Sutro Orizari. Sazije's case, highlighted below, was identified through the ESE paralegal project but taken up by the Roma SOS.

### Problem

Macedonia's Roma community is characterized by high levels of poverty, unemployment, poor health, and a low level of education. Roma remain marginalized from many aspects of public and social life, including access to justice and quality health care services. In 2009, Macedonian law was amended to provide universal health insurance. However, many Roma people living in the slums or temporary dwellings find it difficult to access health insurance, because they often do not have the necessary identity documents to apply for health insurance benefits or have a permanent physical address.

According to Macedonian law, every person has a right to select his or her family doctor, yet many Roma people do not have sufficient information about available health services to realize this right. The doctors of many Roma patients routinely fail to explain their medical conditions adequately, with the result that many chronic disease patients are left unaware of their need for regular checkups. In a study carried out in 2011, ESE found that 76% of patients were not able to procure and use the best therapy, 9.4% said that their information was given away without their consent, and 15.6% said they were denied the right to privacy.

### Actions Taken

The Health for all, Health for Roma project is centered around a paralegal program based in the Roma communities in Shutro Orizari and Delcevo. ESE trained ten community paralegals with an emphasis on human rights and patient care, as well as the structure and composition of the health and judicial systems. ESE then placed the paralegals with CDRIM, KHAM, and RCC. ESE also provides continuous case supervision for the paralegals. The paralegals offer advice, accompany clients to institutions to access services, and prepare requests and other written documents needed to realize their clients' health care rights. The paralegals also refer clients to lawyers, government bodies or civil society organizations.

The paralegals undertake a “door to door” program, which involves home visits to Roma households at least once every two months. The project also involves awareness-raising on specific health issues in the community through roundtable debates and public discussions.

### **Story of Sazije**

When Sazije fell and hurt herself, her family doctor referred her to a specialist who ordered a plaster cast for her arm. However, the cast was placed on Sazije’s lower arm, while her pain was in her shoulder. Sazije asked her son to explain this to the doctor, who told her that if she did not like his treatment, she should seek help elsewhere. A few days later, Sazije visited a different specialist, who removed the cast, which was placed incorrectly, and had to break and reset the bone in order for it to heal properly. Seeking justice for the indignity and pain she suffered, Sazije went to the Humanitarian and Charitable Association of Roma (KHAM) which, together with the Association for Emancipation, Solidarity and Equality of Women (ESE) and Roma SOS, helped her initiate court proceedings against the hospital for discrimination and mistreatment based on her Roma status.

“I cannot describe the difficulties and humiliation I experienced. My pain could be relieved only if justice was done for everything that had happened, in the hopes that others would not have to go through the same ordeal.” –Sazije

### **Results and Lessons Learned**

ESE emphasizes the importance of the educational roundtables run by the paralegals from CDRIM, KHAM, and RCC, which aim to inform the local Roma population about the content and importance of patients’ rights and how to enforce them. The roundtables lead to an increase in the number of clients asking for paralegal assistance and support, and also shift the focus from health insurance and medical negligence-related complaints to complaints related to issues such as discrimination, consent, and confidentiality. The project is consequently helping to address rights issues related to health for the entire community, not just individual claims for damages.

Paralegal assistance and support provided on individual cases, combined with informational and educational workshops, contributed towards better understanding of the importance of patients’ rights and the ways of health protection. Raised awareness and understanding had resulted in resolving concrete problems related to health care and health insurance provision. Both of them are essential for fulfilling the right to health.

Continuous training of paralegals is essential to the success of this project, as this has enabled the paralegals to keep up to date with the law and allows them to come back and ask questions on issues that arise during their work. ESE benefits from close relationships with primary and secondary health care services, as well as with registered general practitioners, gynecologists, dentists, and orthodontists. They also collaborate with the local branches of the Health Insurance Fund and with the local Commissions for Patients’ Rights.

**Association for Emancipation, Solidarity and Equality of Women (ESE)**

Skopje, Macedonia

E-mail: [esem@esem.org.mk](mailto:esem@esem.org.mk)

Website: [www.esem.org.mk](http://www.esem.org.mk)

**Centre for Democratic Development and Initiatives (CDRIM)**

E-mail: [cdrim@mail.net.mk](mailto:cdrim@mail.net.mk)

**Humanitarian and Charitable Association of Roma (KHAM)**

Email: [kham@sonet.com.mk](mailto:kham@sonet.com.mk)

**Roma Resource Center (RCC)**

Skopje, Macedonia

E-mail: [info@rcc.org.mk](mailto:info@rcc.org.mk)

Website: <http://www.rrc.org.mk/>

**Roma S.O.S.**

Prilep, Macedonia

E-mail: [mail@romasosprilep.org](mailto:mail@romasosprilep.org)

Website: [www.romasosprilep.org/](http://www.romasosprilep.org/)



## Example 3: Ending discrimination in access to nationality for children of Nubian descent in Kenya

### Project Type

Litigation: *IHRDA and Open Society Justice Initiative (OSJI) (on behalf of children of Nubian descent in Kenya) v. Kenya*, Communications No 002/09 <http://caselaw.ihrda.org/doc/002.09/>

### Actor

*The Open Society Justice Initiative (OSJI)* uses law to protect and empower people around the world. Through litigation, advocacy, research, and technical assistance, the Justice Initiative promotes human rights and builds legal capacity for open societies. The Justice Initiative works on the following themes: anti-corruption, national criminal justice reform, equality and citizenship, freedom of information and expression, international justice, legal capacity development, and national security and counterterrorism.

*Institute for Human Rights and Development in Africa (IHRDA)* seeks a “continent where all have access to justice, using national, African and international human rights law and mechanisms for the promotion and protection of their rights.”

### Problem

The petitioners alleged that Kenya has historically and unjustly denied Kenyan citizenship to children of Nubian descent. The Nubian population in Kenya arrived during British Colonial rule and were allocated land but denied British citizenship. When Kenya gained independence in 1963, the issue of Nubian citizenship was not addressed and the Government of Kenya continued to deny Kenyan citizenship to persons of Nubian descent.

Upon reaching the age of 18, all Kenyan children apply for an ID card, which is necessary to prove citizenship. For most Kenyan children, this is a simple process; however, Nubian children are forced to go through a long and complex vetting procedure with an uncertain result. Some never receive ID cards. Others receive ID cards only after a long delay.

Lack of citizenship particularly affects Nubian children. They grow up with few life prospects, uncertain as to whether they will be recognized as citizens. Most Nubians live in enclaves of poverty, with no public utilities and limited access to education and health care. The petitioners argued that denial of citizenship to Nubian children was discriminatory and violated the children’s rights to name and nationality, education, and health and health services.

## Violations of the African Children’s Charter

- Non-discrimination (Art. 3)
- Right to name and nationality (Art. 6.2, 6.3, 6.4)
- Right to education (Art. 11.3)
- Right to health and health services (Art. 14.2 (a-c, g))

### Procedure

The Justice Initiative, together with the Institute for Human Rights and Development in Africa (IHRDA), brought a case to the African Committee of Experts on the Rights and Welfare of the Child on behalf of children of Nubian descent in Kenya.

### Arguments and Holdings

#### *Right to birth registration*

Kenya is a State Party to the African Children’s Charter. Article 6 of the Charter provides that:

- (1) Every child shall have the right from his birth to a name.
- (2) Every child shall be registered immediately after birth.

Many Nubian parents find it difficult to register their children at birth. At times, resource limitations and practical obstacles obstruct registration. In addition, health officials discriminate against Nubians and refuse to issue birth certificates to children of Nubian descent. Unregistered children are rendered stateless, as they cannot prove their nationality, place of birth, or parentage. The African Committee concluded that Nubian children must have the *de jure* (legal) and *de facto* (actual) right to registration at birth.

#### *Right to nationality*

Article 6(3) of the Charter provides that “[e]very child has the right to acquire a nationality.” Yet birth certificates do not confer nationality and children must wait until their eighteenth birthday before applying for an ID card to acquire a Kenyan nationality. In this case, the Committee found a strong link between birth registration and nationality and concluded that “the seemingly routine practice . . . of the State Party that leaves children of Nubian descent without acquiring a nationality for a very long period of 18 years is neither in line with the spirit and purpose of Article 6, not promotes children’s best interests, and therefore constitutes a violation of the African Children’s Charter.” (para. 42).

#### *Stateless children*

A birth registration does not confer nationality. An ID card does confer nationality but a child must wait 18 years to receive an ID card, and Nubian children often find it difficult or impossible to obtain an ID card. Therefore, Nubian children are stateless for the first 18 years of their lives, after which they have dim prospects of establishing citizenship and receiving its benefits.

The Committee found the statelessness claim central to the communication. As the Committee pointed out, Article 6(4) of the African Children’s Charter imposes on States Parties to ensure that a child “acquire the nationality of the State in the territory of which he has been born if, at the time of the child’s birth, he is not granted nationality by any other State in accordance with its laws.” Although Kenya maintains its sovereign power to create and maintain its own standards for nationality, it must exercise that power equally and without discrimination. Therefore, although Kenya is not obligated to follow a *jus soli* approach to nationality, the Committee found that Kenya’s *de facto* denial of citizenship to children of Nubian descent violates Article 6(4) of the Charter.

#### *Non-discrimination*

The petitioners alleged that the vetting process for children of Nubian descent to obtain ID cards was discriminatory because they were treated differently. The Committee found that the State should facilitate the process for children who would otherwise be stateless. The Committee found Kenya to be in violation of Article 3.

*Right to health*

The Committee began by referring to two cases heard by the African Commission under Article 16 of the African Charter of Human and Peoples' Rights (ACHPR). The Committee stated, "African jurisprudence places a premium on both the right to health care and the right to underlying conditions of health." (para. 59) The Committee examined the content of Article 14 under the African Children's Charter and found that the provisions were similar in content to Article 16 of the ACHPR and that the African Commission's findings 'bear significant relevance.' (para. 60) The Committee did not elaborate on specifics of health care provision to children of Nubian descent, but said plainly: "The affected [Nubian] children had less access to health services than comparable communities who were not composed of children of Nubian descent. There is *de facto* inequality in their access to available health care resources, and this can be attributed in practice to their lack of confirmed status as nationals of the Republic of Kenya. Their communities have been provided with fewer facilities and a disproportionately lower share of available resources, as their claims to permanence in the country have resulted in health care services in the communities in which they live being systematically overlooked over an extended period of time." With that, the Committee found a violation of Article 14(2)(b,c,g).

*Right to education*

Using similar reasoning, the Committee found that children of Nubian descent had less access to education facilities and experienced *de facto* inequality in access. The Committee further found that the affected communities had been provided with fewer schools and that their right to education had not been recognized and provided for. The Committee found a violation of Article 11(3).

**Commentary and Analysis**

The Committee found that Kenya's actions violated the Charter's provisions protecting children's right to nationality, observing that statelessness is the antithesis of the best interests of the child. The Committee also found that Kenya's vetting system unlawfully discriminates against Nubian children in violation of Article 3, leaving them stateless or at risk of statelessness with no legitimate hope of gaining recognition of their citizenship. As a result, Nubian children lack access to adequate health care and education, in violation of Kenya's obligations to provide the highest attainable standard of health and education to all children (Articles 14(2)(a)-(c), (g) and Article 11(3), respectively).

The Committee issued five detailed recommendations, including legislative and administrative reforms, an obligation to consult with affected communities in developing implementation strategies, and the requirement that Kenya implement a non-discriminatory birth registration system. It also established implementation monitoring mechanisms, including an obligation that Kenya report back on implementation within six months, and that a dedicated Committee member monitor implementation.

## Additional Resources

### *Litigation documents*

- Letter of Introduction. [www.opensocietyfoundations.org/sites/default/files/minorsletter\\_2009414.pdf](http://www.opensocietyfoundations.org/sites/default/files/minorsletter_2009414.pdf)
- Submissions on the Merits. [www.opensocietyfoundations.org/sites/default/files/nubian-minors-submission-20100603.pdf](http://www.opensocietyfoundations.org/sites/default/files/nubian-minors-submission-20100603.pdf)
- ACERWC: Nubian Minors, Decision, March 22, 2011. [www.opensocietyfoundations.org/sites/default/files/ACERWC-nubian-minors-decision-20110322.pdf](http://www.opensocietyfoundations.org/sites/default/files/ACERWC-nubian-minors-decision-20110322.pdf)

### *Featured Works*

- Sebastian Kohn, The Nubian Predicament: A Story about Colonia Legacy, Discrimination, and Statelessness. [www.opensocietyfoundations.org/voices/nubian-predicament-story-about-colonial-legacy-discrimination-and-statelessness](http://www.opensocietyfoundations.org/voices/nubian-predicament-story-about-colonial-legacy-discrimination-and-statelessness)
- Laura Bingham, On the Agenda in the Algiers: African Children's Rights and Nationality. [www.opensocietyfoundations.org/voices/agenda-algiers-african-childrens-rights-and-nationality](http://www.opensocietyfoundations.org/voices/agenda-algiers-african-childrens-rights-and-nationality)

## Example 4: Roma Health mediators in Romania

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### Project Type

Advocacy

### Organization

Founded on April 4, 1993, Romani CRISS is a human rights NGO with a mission to “defend the rights of Roma in Romania” The organization focuses on issues of education, health, civic mobilization, legal assistance, promoting ethnic identity and other human-rights campaigns. Romani CRISS first pioneered Roma mediation in 1992 as a community conflict mitigation program.

The Public Health Program of Open Society Foundation created and manages a Roma Health Project which has supported the Roma health mediators since 2001.

### Problem

Roma are disproportionately excluded from accessing health care services, and they encounter prevalent discrimination by providers. In a 2005 survey among 717 Romanian Roma women, 70% reported discrimination from health providers based on their race/ethnicity. Roma women face particular problems, including coerced sterilization and separate maternity wards. There is no administrative mechanism to address these abuses against the Roma and other vulnerable groups.

### Actions Taken

Romani CRISS developed a program in Romania whereby health mediators helped improve communication between the Roma community and health providers through the use of health mediators. Health mediation was designed to improve the Roma health status and access to health care services. The health mediators also refer cases of abuse and discrimination in health facilities to human rights monitors for documentation and legal advocacy.

The objectives of the program are to facilitate communication between medical personnel and Roma communities, and to increase the efficacy of public health interventions. Mediators are usually Roma women with an average level of education, recommended by local communities and agreed upon by medical practitioners, who have successfully completed a brief period of training. Their main responsibilities are to serve as liaisons between communities and health care practitioners; to collect data on the health situation in the community; to facilitate Roma access to health care; to provide health education; and to support public health interventions in Roma communities.

Romani CRISS negotiated an agreement with the Ministry of Health and the Organization for Security and Co-operation in Europe Office for Democratic Institutions and Human Rights. Romani CRISS trains Roman Health Mediators (RHM), who are employees of the public health system. Mediators are from Roma communities but are situated in health clinics to improve communication with providers. They educate communities on how to access health services and sensitize doctors on Roma health needs.

In 2007, Romani CRISS initiated a program to create a link between health mediators and the human rights monitors. Health mediators were trained in human rights, and human rights monitors were trained in health issues. This way, the mediators knew to refer cases of discrimination or abuse to the monitors for documentation, and they could sensitize communities on human rights issues. The monitors would then document cases of discrimination in health care settings and bring them for redress before the National Council to Combat Discrimination, the College of Physicians, and other institutions.

## **Recommendations for Health Mediator Programs for Minority Populations:**

1. Ensure the institutionalization of health mediator programs
2. Include doctors, nurses, social workers, and other professionals in health mediator trainings and professional events
3. Support the development of health mediator professional associations
4. Ensure that program monitoring focuses on outcomes as much as possible
5. Ensure supportive supervision
6. Increase the number of mediators to meet the current needs of the population they serve
7. Ensure continuing education
8. Create opportunities for health and social policy officials to learn from health mediator experiences
9. Ensure that health mediators have a secure contract and salary
10. Ensure that health mediators earn a living wage
11. Ensure that health mediators have the money and other tools required for the tasks

## **Larger Health Policy Recommendations:**

1. Ensure that health education materials that health mediators and health professionals distribute are adapted for the audience
2. Ensure that mediation is part of a continuum of services available to excluded populations
3. Better integrate minority health concerns into health policy
4. Ensure that other steps are taken to reduce poverty among the minority population
5. Ensure that laws relating to personal documentation and health insurance coverage are not too onerous for minority groups
6. Take steps to increase routine vaccination coverage
7. Engage minority men in sexual and reproductive health programs
8. Design programs that take a community-building approach to minority health
9. Increase the number of minority health and social service professionals

## **Challenges to Roma Health Mediation programs:**

1. Low salaries for RHMs
2. Inadequate supervision
3. Lack of professional development opportunities
4. Governments fail to leverage RHM experience
5. Persistence of focus on health care and not the social determinants of health
6. Insufficient cooperation with other actors in the health care system
7. Lack of support because of decentralization
8. Contract and pay insecurity
9. Physicians rely on RHMs to aid Roma clients, relieving themselves of this responsibility

## Results and Lessons Learned

Evidence suggests that mediators both directly affect health and change the nature of the community in which programs occur. RHMs increase access to health care and other social services, and increase health literacy among Roma populations. The reporting system operates as a check on rights violations. RHMs do not address structure discrimination, poor health policies, or poverty levels.

The successes of the program include the collaboration between governmental and nongovernmental structures in the planning and implementation of health mediation; the number of women trained and hired as health mediators; the number of beneficiaries; and the geographical coverage, but also the transferability in other European countries that have a significant number of Roma, such as Bulgaria or Macedonia. Other strong points of the program are the focus on preventive instead of curative care; the contribution towards increasing knowledge pertaining to Roma health; and the assistance provided to some of the most vulnerable categories of Roma, particularly the persons lacking identity documents.

With the adoption of its new strategic plan in 2010, Open Society Foundation's Roma Health Project (RHP) shifted focus from health education campaigns and service delivery to human rights-based advocacy. RHP's key achievements since that time include:

- *Legal strategies.* Jointly with the Open Society Foundation's Law and Health Initiative (LAHI), RHP's partners in Macedonia, Romania, and Serbia have piloted legal and paralegal services to remedy human rights abuses against Roma in health settings and to address systemic barriers to health care such as lack of identification documents and health insurance. In Romania, RHP is supporting the European Roma Rights Center to investigate the differential infant mortality rates between Roma and non-Roma communities, and to launch litigation aimed at establishing a government duty to collect ethnically disaggregated data as part of its obligation to promote non-discrimination in health care.
- *Innovations in accountability.* Jointly with Open Society Foundation's Accountability and Monitoring in Health Initiative (AMHI), RHP's partners in Bulgaria, Macedonia, and Romania have successfully used community monitoring to press governments to implement and pay for health programs described in national policy documents. In Bulgaria, a series of "community inquiries" into local health services by over 500 Roma women resulted in a 12% increase in Roma accessing medical examinations free of charge over a period of four months. In Macedonia, a community investigation into measles outbreaks linked to differential immunization rates led to a targeted and long overdue government budget allocation for immunization services in Roma communities.
- *Advocacy and capacity-building.* In Bulgaria, Romania, Macedonia, and Serbia, RHP has built a cohort of NGOs advancing Roma health using rights-based advocacy. In Bulgaria, RHP's partner advocated in 2011 to include Roma as a distinct group in national health policies and guidelines for EU funds. In Romania, RHP's partner contributed to a General Policy Recommendation on Roma Health, which was circulated to all relevant government agencies developing Romania's national Roma strategy. In Macedonia, partners secured a government commitment to finance the salaries, training, and logistics for nine Roma Health Mediators—members of the Roma community who are trained to act as an interface between the Roma community and the health system. In Ukraine, RHP's partner raised third-party funding that more than tripled the number of Roma health mediators in the country.



- *OSF/RHP and European Public Health Alliance (EPHA) Roma health fellows.* In 2012, OSF's Roma Health Project together with EPHA are launching a two-year fellowship to train and mentor two Roma health EU advocates. The fellowship aims to increase the capacity of the Roma community for leadership on Roma health at EU level by facilitating advocacy efforts for establishment of an EU Roma Health Strategy. More information is available at: [www.epha.org/spip.php?article5017](http://www.epha.org/spip.php?article5017).
- *Roma health at the European Union.* As members of the Roma Civil Society Contact Group on the Right to Health, established in 2012 by the World Health Organization and the Office of the High Commissioner for Human Rights, seven RHP partners have provided policy guidance on health-focused components of National Roma Integration Strategies (NRIS), the EU Platform for Roma Inclusion, the Decade of Roma Inclusion, and national health programs. In June 2012, one of these partners convened a European Commission hearing on strengthening monitoring and evaluation of NRIS recommendations that resulted after the hearing and the link with more information about the EU hearing: <http://amalipe.com/index.php?nav=news&id=1234&lang=2>.
- RHP is participating in an OSF-wide effort to leverage the European Cohesion Policy towards greater Roma integration by proposing ex ante conditionalities for Structural Funds for health.
- *Individual leadership.* Together with the Roma Education Fund (REF), RHP spearheaded the Roma Health Scholarship Program (RHSP), which since 2008 has awarded a total of 676 scholarships for tertiary and vocational medical education in Romania, Bulgaria, Macedonia, and Serbia. In 2010, RHP/REF's partners in Romania secured €4,800,000 in European Structural Funds to sustain RHSP over three years. RHSP's combination of scholarships, preparatory courses, advocacy training, mentorship, and media outreach is creating a generation of Roma health professionals with the potential to challenge deep-rooted anti-Roma prejudice within health systems.

### **Romani CRISS**

Bucharest, Romania

Email: [office@romanicriss.org](mailto:office@romanicriss.org)

Website: [www.romanicriss.org](http://www.romanicriss.org)

## Example 5: Campaign for indigenous health equality in Australia

### Project

Advocacy

### Actor/Organization

The Australian Human Rights and Equal Opportunity Commission (HREOC) was created by law in 1986. The position of Aboriginal and Torres Strait Islander Social Justice Commissioner was created within the HREOC in 1993 with the intent to advance the rights of indigenous peoples through reporting and research.

In 2005, the Aboriginal and Torres Strait Islander Social Justice Commissioner released a report including a chapter on indigenous health inequality in Australia. The chapter outlines a human rights based campaign for achieving Aboriginal and Torres Strait Islander health equality within a generation. This resulted in the creation of a coalition on Aboriginal Health called “Close the Gap” in 2006. Close the Gap is a coalition of indigenous and non-indigenous health and human rights organizations who are working in the Australian government to improve health equality for indigenous populations. The group is led by the Aboriginal and Torres Strait Islander Social Justice Commissioner.

### Problem

Indigenous peoples in Australia experience unequal access to the right to health. The average Australian woman is expected to live 82 years, while an indigenous woman can expect to live only 64.8 years. The Social Justice Report provides further evidence of the inequality in health outcomes for indigenous peoples.

The report recognizes that the inequality in health status of indigenous people is linked to systemic discrimination. Indigenous people have restricted access to health services as well as inadequate health infrastructure in some communities, including safe drinking water, proper sewage systems, garbage collection, and adequate housing.

“It is not credible to suggest that one of the wealthiest nations in the world cannot solve a health crisis affecting less than three per cent of its citizens.”

— Tom Calma

*Aboriginal and Torres Strait Islander Social Justice Commissioner  
Social Justice Report 2005*

### Actions Taken

The Social Justice Report 2005 discusses the health inequities among indigenous people and the current policy approach and proposes an approach to achieving health equality for Indigenous people within a generation. Based upon this proposed human rights-based approach to health equality, a coalition was formed to realize the goals of the approach by 2030 – Close the Gap campaign.

Close the Gap adopted the goals from the 2005 report and has moved forward to develop partnerships with indigenous peoples as well as government officials and NGOs. The campaign is pushing to develop a National Plan with concrete targets that the government would be committed to achieving.

### Results and Lessons Learned

Close the Gap has made some impressive inroads since its inception in 2006. In 2008, they held a National Indigenous Health Equality Summit, during which the former prime minister and opposition leader signed the Close the Gap Statement of Intent. When the government signed the National Partnership Agreement, it also pledged \$1.6 billion dollars to the effort. In addition, Close the Gap secured about \$5 billion in additional resources with seven additional National Partnership Agreements.

In July 2008, the Close the Gap National Indigenous Health Equality Targets were published and presented to the Federal Health Minister. Developed by a range of experts, the Health Equality Targets aimed to provide a framework of priorities and key indicators of progress towards health equality. The government also agreed to make an annual report to parliament on its progress, beginning in 2009. The Close the Gap campaign has provided shadow reports to the annual report, providing their assessment of the government's progress

In addition to partnerships with the government and NGOs, Close the Gap has also developed significant public outreach and participation efforts. There is now an annual National Close the Gap Day in Australia with activities and events, where in 2012, 130,000 Australians participated. There is also a public Close the Gap pledge.

In late 2011, these developments culminated in emergence of the National Health Leadership Forum (NHLF). While linked to the Close the Gap Campaign, the NHLF functions independently and was created with a specific purpose – to serve as an interface for government to partner with Aboriginal and Torres Strait Islander peoples and their organizations in the development and implementation of health policy that affects these populations.

### Additional Resources

**Close the Gap: Campaign for Indigenous Health Equality**

[http://humanrights.gov.au/social\\_justice/health/index.html](http://humanrights.gov.au/social_justice/health/index.html)

**Close the Gap: Oxfam Australia (Links to Close the Gap Pledge and National Close the Gap Day)**

[www.oxfam.org.au/explore/indigenous-australia/close-the-gap/](http://www.oxfam.org.au/explore/indigenous-australia/close-the-gap/)

**Social Justice Report 2005 - Chapter 2: Achieving Aboriginal and Torres Strait Islander health equality with- in a generation – A human rights based approach**

[http://humanrights.gov.au/social\\_justice/sj\\_report/sjreport05/pdf/SocialJustice2005.pdf](http://humanrights.gov.au/social_justice/sj_report/sjreport05/pdf/SocialJustice2005.pdf)

**National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes Implementation**

**Plan:** [www.health.gov.au/internet/main/Publishing.nsf/Content/closinggap-tacklingchronicdisease/\\$File/commonwealth\\_implementation\\_plan.pdf](http://www.health.gov.au/internet/main/Publishing.nsf/Content/closinggap-tacklingchronicdisease/$File/commonwealth_implementation_plan.pdf)

**Close the Gap Community Guide:** [http://humanrights.gov.au/social\\_justice/health/ctg\\_community.pdf](http://humanrights.gov.au/social_justice/health/ctg_community.pdf)

## 5. WHAT STEPS CAN GOVERNMENT AND KEY STAKEHOLDERS TAKE TO IMPROVE THE HEALTH STATUS OF MINORITY POPULATIONS?

The preceding case studies are concrete examples of projects using human rights mechanisms to improve access to health care and the health status of minority individuals and communities. The spectrum of barriers to health care for minority populations is broad, including discrimination in health care settings, a legacy of ineffective public policies, and geographic isolation. The table below presents some steps that governments and other key stakeholders can take immediately to begin to overcome these obstacles.

### Ten steps for overcoming barriers to health care for minority populations:

#### Governments:

1. Appoint minority representatives to participate in the design, implementation, and evaluation of health programs and policies that affect their lives.
2. Ensure that policies and legislation address social factors that determine health and the needs of minorities. Interventions that aim to improve housing, for example, are critical to reducing TB infections.
3. Support the collection of ethnically disaggregated data and, based on this data, allocate resources to populations most in need of basic health services. Communities should be involved in the data collection and analysis process.
4. Train health care workers in communicating and working with minority and marginalized populations.
5. Establish an ombudsperson office or other monitoring mechanism in health care systems to follow up reports of abuse or discrimination in health care settings.
6. Grant under-represented minority students incentives and assistance to enter health care professions.

#### Civil society, donors, researchers, media:

7. Civil society should become more familiar with instruments designed to protect and promote human rights, including the right to health for minorities.
8. Donors should invest in the institutional and capacity development of Roma leadership to engage effectively on policy issues affecting access to health and social services.
9. Academic, government, and other research communities should explore the inequities in access to health care for minorities and other marginalized populations.
10. Media should investigate and report systemic causes of the inequity in health status between minorities and the majority population in a balanced and fair manner.

*Source:* Open Society Institute Public Health Program. *Left Out: Roma and Access to Health Care in Eastern Europe and South Eastern Europe*, 2007.

## 6. WHERE CAN I FIND ADDITIONAL RESOURCES ON MINORITY COMMUNITIES, HEALTH, AND HUMAN RIGHTS?

A list of commonly used resources on health and human rights in minority communities follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Declarations and Statements
- D. Minority Rights (General)
- E. Right to Non-Discrimination
- F. Right to the Highest Attainable Standard of Health
- G. Right to Education
- H. Right to Participate in Public Life
- I. Right to Bodily Integrity
- J. Rights of Minority Women
- K. Rights of Minority Children
- L. Rights of the Roma
- M. Training Guides and Manuals
- N. Websites
- O. Websites focused on Roma Rights

## A. International Instruments

### *Binding*

- ILO
  - *Discrimination (Employment and Occupation) Convention*, No. 111 (1958). [www.ilo.org/wcmsp5/groups/public/---ed\\_norm/---declaration/documents/publication/wcms\\_decl\\_fs\\_85\\_en.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_norm/---declaration/documents/publication/wcms_decl_fs_85_en.pdf).
  - *Declaration on Fundamental Principles and Rights at Work* (1998). [www.ilo.org/declaration/thedeclaration/textdeclaration/lang-en/index.htm](http://www.ilo.org/declaration/thedeclaration/textdeclaration/lang-en/index.htm).
- UNESCO
  - *Convention against Discrimination in Education* (1960). [http://portal.unesco.org/en/ev.php-URL\\_ID=12949&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=12949&URL_DO=DO_TOPIC&URL_SECTION=201.html).
  - *Convention for the Safeguarding of the Intangible Cultural Heritage* (2003). [www.unesco.org/culture/ich/index.php?lg=en&pg=00022](http://www.unesco.org/culture/ich/index.php?lg=en&pg=00022).
  - *Convention on the Protection and Promotion of the Diversity of Cultural Expressions* (2005). [http://portal.unesco.org/en/ev.php-URL\\_ID=31038&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31038&URL_DO=DO_TOPIC&URL_SECTION=201.html).
- UN Conference of Plenipotentiaries, *Convention relating to the Status of Refugees and Stateless Persons* (1951) and *Protocol Relating to the Status of Refugees* (1967). [www.unhcr.org/pages/49da0e466.html](http://www.unhcr.org/pages/49da0e466.html).
- UN General Assembly
  - *Convention on the Prevention and Punishment of the Crime of Genocide* (1948). <http://treaties.un.org/doc/Publication/UNTS/Volume%2078/volume-78-I-1021-English.pdf>.
  - *International Convention on the Elimination of All Forms of Racial Discrimination*, CERD/C/351/Add.1 (1965). [www.ohchr.org/EN/ProfessionalInterest/Pages/CERD.aspx](http://www.ohchr.org/EN/ProfessionalInterest/Pages/CERD.aspx).

### *Nonbinding*

- UN Commission on Human Rights, *Commentary of the Working Group on Minorities to the United Nations Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities*, E/CN.4/Sub.2/AC.5/2005/2 (2005). [http://www.ohchr.org/Documents/Events/Minority2012/Go513385\\_en.pdf](http://www.ohchr.org/Documents/Events/Minority2012/Go513385_en.pdf)
- UN Committee on the Elimination of Racial Discrimination (CERD).
  - General Recommendations. [www2.ohchr.org/english/bodies/cerd/comments.htm](http://www2.ohchr.org/english/bodies/cerd/comments.htm).
  - *Guidelines for the early warning and urgent action procedures*, Annual report A/62/18, Annexes, Chapter III (2007). [www2.ohchr.org/english/bodies/cerd/docs/Revised\\_Guidelines\\_2007\\_en.doc](http://www2.ohchr.org/english/bodies/cerd/docs/Revised_Guidelines_2007_en.doc).
- UN General Assembly.
  - *Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief*, Resolution 36/55 (1981). [www.unesco.org/most/migration/full\\_dec\\_elim1.htm](http://www.unesco.org/most/migration/full_dec_elim1.htm).
  - *Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities*, Resolution 47/135 (1992) [United Nations Minority Declaration]. [www.ohchr.org/Documents/Publications/GuideMinoritiesDeclarationen.pdf](http://www.ohchr.org/Documents/Publications/GuideMinoritiesDeclarationen.pdf).
- UN Human Rights Council, Forum on Minority Issues, *Compilation of Recommendations of the First Four Sessions 2008-2011*. [www.ohchr.org/EN/HRBodies/HRC/Minority/Pages/ForumIndex.aspx](http://www.ohchr.org/EN/HRBodies/HRC/Minority/Pages/ForumIndex.aspx).

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<sup>72</sup> The European Union (EU) and the Council of Europe (COE) represent separate and distinct jurisdictions. While EU member states are automatically bound by EU instruments, COE member states are not bound by COE instruments unless they choose to be. Additionally, COE members are not necessarily EU members, and COE instruments are not binding on the EU itself.



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- European Union, Agency for Fundamental Rights: <http://fra.europa.eu/en>.
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- Health Poverty Action: [www.healthpovertyaction.org](http://www.healthpovertyaction.org).
- Human Rights First, Fighting Discrimination Program: [www.humanrightsfirst.org/our-work/fighting-discrimination](http://www.humanrightsfirst.org/our-work/fighting-discrimination).
- International Movement Against All Forms of Discrimination and Racism (IMADR): [www.imadr.org](http://www.imadr.org).
- International Society for Equity in Health (ISEqH): [www.iseqh.org](http://www.iseqh.org).
- Minority Rights Group International: [www.minorityrights.org](http://www.minorityrights.org).
- OHCHR, “Minorities”: [www.ohchr.org/EN/Issues/Minorities/Pages/MinoritiesIndex.aspx](http://www.ohchr.org/EN/Issues/Minorities/Pages/MinoritiesIndex.aspx).
- OSCE, High Commissioner on National Minorities”: [www.osce.org/hcnm](http://www.osce.org/hcnm).
- UN Human Rights Council, Forum on Minority Issues: [www.ohchr.org/EN/HRBodies/HRC/Minority/Pages/ForumIndex.aspx](http://www.ohchr.org/EN/HRBodies/HRC/Minority/Pages/ForumIndex.aspx).
- UN Independent Expert on minority issues: [www.ohchr.org/en/Issues/Minorities/IEExpert/Pages/IEminorityissuesIndex.aspx](http://www.ohchr.org/en/Issues/Minorities/IEExpert/Pages/IEminorityissuesIndex.aspx).
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- UN Special Rapporteur on freedom of religion or belief: [www.ohchr.org/EN/Issues/FreedomReligion/Pages/FreedomReligionIndex.aspx](http://www.ohchr.org/EN/Issues/FreedomReligion/Pages/FreedomReligionIndex.aspx).

## O. Websites focused on Roma rights

- Council of Europe: Roma and Travellers: [www.coe.int/T/DG3/RomaTravellers/Default\\_en.asp](http://www.coe.int/T/DG3/RomaTravellers/Default_en.asp).
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- Fundacion Secretariado Gitano: [www.fsgg.org](http://www.fsgg.org).
- Open Society Foundation
  - Roma Initiatives Office: [www.opensocietyfoundations.org/about/programs/roma-initiatives-office](http://www.opensocietyfoundations.org/about/programs/roma-initiatives-office).
  - Roma Participation Program: [www.soros.org/initiatives/roma/focus/rpp](http://www.soros.org/initiatives/roma/focus/rpp).
- Roma Education Fund (REF). [www.romaeducationfund.hu](http://www.romaeducationfund.hu)
- Roma Women Network: [www.romawoman.org](http://www.romawoman.org).
- Romani Center for Social Intervention and Studies (Romani CRISS): [www.romanicriss.org](http://www.romanicriss.org).
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- World Bank, “World Bank and the Roma”: [www.worldbank.org/roma](http://www.worldbank.org/roma)

## 7. WHERE CAN I FIND ADDITIONAL RESOURCES ON INDIGENOUS PEOPLES, HEALTH, AND HUMAN RIGHTS?

A list of commonly used resources on health and human rights of indigenous peoples follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Indigenous Rights - General
- D. Right to Health
- E. Right to Housing
- F. Rights of Indigenous Women
- G. Rights of Indigenous Children
- H. Training, Database & Study Guides
- I. Websites

### A. International Instruments

#### Binding

- ILO, *Indigenous and Tribal Peoples Convention*, No. 169 (1989).  
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- *Advice No. 1 (2009) on the Indigenous Peoples' Right to Education*
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### Binding

- Inter-American Commission on Human Rights, *American Declaration on the Rights of the Indigenous Peoples* OEA/Ser/L/V/II.95 Doc.6 (February 26, 1997). [www.cidh.oas.org/indigenas/chap.2g.htm](http://www.cidh.oas.org/indigenas/chap.2g.htm).

## C. Indigenous Rights - General

- African Commission on Human and Peoples' Rights, *Indigenous Peoples in Africa: The Forgotten Peoples? The African Commission's work on indigenous peoples in Africa* (2006). [www.ilo.org/indigenous/Resources/Publications/WCMS\\_115929/lang-en/index.htm](http://www.ilo.org/indigenous/Resources/Publications/WCMS_115929/lang-en/index.htm).
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- Barnsley I, "The Right to Health of Indigenous Peoples in the Industrialized World: A Research Agenda" *Health and Human Rights* 9, no. 1 (2006): 43-54. [www.hhrjournal.org/archives-pdf/4065389.pdf.banned.pdf](http://www.hhrjournal.org/archives-pdf/4065389.pdf.banned.pdf).
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## E. Right to Housing

- United Nations Human Settlements Programme, Indigenous peoples’ right to adequate housing: A global overview (2005). [www.ohchr.org/Documents/Publications/IndigenousPeoplesHousingen.pdf](http://www.ohchr.org/Documents/Publications/IndigenousPeoplesHousingen.pdf).

## F. Rights of Indigenous Women

- Banda F and Chinkin C, *Gender, Minorities and Indigenous Peoples* (Minority Rights Group International, 2004). [www.minorityrights.org/download.php?id=115](http://www.minorityrights.org/download.php?id=115).
- Human Rights Watch, *Those Who Take Us Away: Abusive Policing and Failures in Protection of Indigenous Women and Girls in Northern British Columbia, Canada* (2013). [www.hrw.org/reports/2013/02/13/those-who-take-us-away-o](http://www.hrw.org/reports/2013/02/13/those-who-take-us-away-o).
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- UNFPA, Forum: Indigenous Women in Latin America. [www.unfpa.org/rights/indigenous.htm](http://www.unfpa.org/rights/indigenous.htm).

## G. Rights of Indigenous Children

(See also Chapter 6: Children’s Health and Human Rights)

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- Miller M, *Ensuring the rights of indigenous children*, Innocenti Digest 11 (UNICEF, 2004). [www.unicef-irc.org/publications/356](http://www.unicef-irc.org/publications/356).
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- UNICEF, “Children of minorities or of indigenous peoples”, *Implementation Handbook for the Convention on the Rights of the Child* (2007).
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  - *Checklists*: [www.unicef.org/ceecis/handbook\\_2\\_CHECKLISTS.pdf](http://www.unicef.org/ceecis/handbook_2_CHECKLISTS.pdf).

## H. Training, Database and Study Guides

- ILO, *Indigenous & Tribal People's Rights in Practice - A Guide to ILO Convention No. 169* (2009). [www.ilo.org/wcmsp5/groups/public/---ed\\_norm/---normes/documents/publication/wcms\\_106474.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_norm/---normes/documents/publication/wcms_106474.pdf).
- ILO, "PRO 169 Training Tool Box on Indigenous Peoples' Rights". [www.pro169.org](http://www.pro169.org)
- University of Minnesota Human Rights Center, "STUDY GUIDE: The Rights of Indigenous Peoples" (2003). [www1.umn.edu/humanrts/edumat/studyguides/indigenous.html](http://www1.umn.edu/humanrts/edumat/studyguides/indigenous.html).
- University of Pretoria, Centre for Human Rights, Indigenous Peoples' Rights Database: [www1.chr.up.ac.za/chr\\_old/indigenous/index.html](http://www1.chr.up.ac.za/chr_old/indigenous/index.html).

## I. Websites

- Amnesty International Canada, "Indigenous Peoples". [www.amnesty.ca/our-work/issues/indigenous-peoples](http://www.amnesty.ca/our-work/issues/indigenous-peoples)
- Asia Indigenous Peoples Pact (AIPP). [www.aippnet.org](http://www.aippnet.org)
- Asian Human Rights Commission, "Indigenous People". [www.humanrights.asia/issues/indigenous-people](http://www.humanrights.asia/issues/indigenous-people)
- Consejo Civico de Organizaciones Populares e Indígenas de Honduras (COPINH): [www.copinh.org](http://www.copinh.org).
- Cultural Survival: [www.culturalsurvival.org](http://www.culturalsurvival.org).
- European Union, "EU policy on indigenous peoples": [http://eeas.europa.eu/human\\_rights/ip/index\\_en.htm](http://eeas.europa.eu/human_rights/ip/index_en.htm).
- First Peoples Worldwide: [www.firstpeoples.org](http://www.firstpeoples.org).
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  - Australian Human Rights Commission, "Aboriginal & Torres Strait Islander Social Justice": [www.humanrights.gov.au/social\\_justice/index.html](http://www.humanrights.gov.au/social_justice/index.html).
  - Government of Canada, "Aboriginal Affairs and Northern Development Canada": [www.aandc-aadnc.gc.ca](http://www.aandc-aadnc.gc.ca).
  - U.S. Government, Bureau of Indian Affairs: [www.bia.gov](http://www.bia.gov).
- ILO, "Indigenous and Tribal Peoples": [www.ilo.org/indigenous](http://www.ilo.org/indigenous).
- Indigenous Human Rights Network Australia: [www.ihrna.info](http://www.ihrna.info).
- Indigenous Peoples of Africa Coordinating Committee (IPACC): [www.ipacc.org.za/eng/default.asp](http://www.ipacc.org.za/eng/default.asp).
- Indigenous Peoples Links (PIPLinks): <http://int.piplinks.org>.
- International Work Group on Indigenous Affairs: [www.iwgia.org](http://www.iwgia.org).
- Legal Assistance Centre: [www.lac.org.na](http://www.lac.org.na).
- National Congress of American Indians: [www.ncai.org](http://www.ncai.org).
- Survival International: [www.survivalinternational.org](http://www.survivalinternational.org).
- UNFPA, "Putting Rights into Practice: Addressing the Rights of Indigenous Peoples": [www.unfpa.org/rights/people.htm](http://www.unfpa.org/rights/people.htm).

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- “Indigenous Peoples at the United Nations”: [www.un.org/esa/socdev/unpfii/en/session\\_fifth.html](http://www.un.org/esa/socdev/unpfii/en/session_fifth.html).
- UN Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance. [www.ohchr.org/EN/Issues/Racism/SRRacism/Pages/IndexSRRacism.aspx](http://www.ohchr.org/EN/Issues/Racism/SRRacism/Pages/IndexSRRacism.aspx).
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- UN Special Rapporteur on the rights of indigenous peoples. [www.ohchr.org/EN/Issues/IPeoples/SRIndigenousPeoples/Pages/SRIPeoplesIndex.aspx](http://www.ohchr.org/EN/Issues/IPeoples/SRIndigenousPeoples/Pages/SRIPeoplesIndex.aspx)



## 8. WHAT ARE KEY TERMS RELATED TO MINORITY HEALTH AND HUMAN RIGHTS?

### C

#### ***Civil rights***

Rights individuals have in their role as citizens in relation to the state.

#### ***Collective rights***

Rights associated with a community or people.

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### D

#### ***Direct discrimination***

Any distinction, exclusion, restriction, or preference based on race, color, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment, or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural, or any other field of public life (ICERD).

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### F

#### ***Forcible assimilation***

Policies which seek to forcibly incorporate a minority group into the majority population by erasing any distinctiveness in culture, religion, language, or practices.

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### G

#### ***Gender equity***

Equality in social roles and opportunities available to women and men.

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### H

#### ***Health equity***

Concern with reducing unequal opportunities for health associated with membership in a less privileged social group, such as an ethnic minority.

#### ***Health inequality***

Systematic and potentially remediable differences in one or more aspects of health across populations or population groups defined socially, economically, demographically, or geographically.

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### I

#### ***Indigenous people***

People descended from populations which inhabited the country at the time of conquest or colonization, or the establishment of present state boundaries, and who retain some or all of their social, economic, and political institutions (ILO). This term is somewhat problematic in the African context, where many countries define it exclusively against European colonialism and in reference to the majority Bantu population, rather than just for Khoesan populations like the San.

#### ***Indirect discrimination***

An apparently neutral practice or criterion, which nonetheless places a group at social disadvantage based on group characteristics.

**M****Minority**

Groups with unequal power compared with the dominant majority and which may need protection from that majority (Minority Rights Group International). Minorities are defined by number (smaller than the majority population), non-dominance, and differences in ethnicity, culture, religion, or language.

“[A] group numerically inferior to the rest of the population of a state, in a non-dominant position, where members-being national of the state-possess ethnic, religious, linguistic characteristics differing from those of the rest of the population and show, if only implicitly, a sense of solidarity, directed towards preserving their culture, tradition, religion or language.”<sup>73</sup>

**Minority rights**

A rights-based approach stressing the importance of cultural preservation as a means of improving the condition of minority groups. This embodies two separate concepts: first, normal individual rights as applied to members of racial, ethnic, class, religious, linguistic, or sexual minorities, and second, collective rights accorded to minority groups.

**S****Self-identification**

Determination of belonging to a minority group made by the individuals themselves.

**Social determinants of health**

The broad range of factors that contribute to a person’s health including nutrition, housing, education, availability of social services, income, etc.

**Social exclusion**

The prevention of people from participating fully in economic, social, and civil life and/or when their access to income and other resources (personal, family, social, and cultural) is so inadequate as to exclude them from enjoying a standard of living and quality of life regarded acceptable by the society in which they live.

**Social integration**

Policies which seek to integrate a minority without coercion into the majority society, while ensuring the protection of individual rights.

<sup>73</sup> Capotorti F, *Study on the Rights of Persons Belonging to Ethnic, Religious and Linguistic Minorities*, U.N. Doc E/CN.4/Sub.2/384/Rev.1, U.N. Sales No. E.78.XIV.1 (1979): 96.

# CHAPTER 8



## LGBTI, HEALTH AND HUMAN RIGHTS

“...[T]here is nothing new or special about the right to life and security of the person, the right to freedom from discrimination. These and other rights are universal ... enshrined in international law but denied to many of our fellow human beings simply because of their sexual orientation or gender identity.”

— United Nations High Commissioner for Human Rights Navi Pillay, 2012

**Health and Human Rights Resource Guide**

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Cover photograph courtesy of U.S.Consulate General Chennai, “LGBT activists at Chennai’s fourth annual Pride March at Elliot’s Beach on Sunday, June 24, 2012.”

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# INTRODUCTION

This chapter will introduce you to key issues and resources in the health and human rights of lesbian, gay, bisexual, transgender and intersex (LGBTI) persons. This chapter is organized into six sections that answer the following questions:

1. How is health a human rights issue for LGBTI persons?
2. What are the most relevant international and regional human rights standards related to LGBTI health?
3. What is a human rights-based approach to advocacy, litigation and programming?
4. What are some examples of effective human rights-based work in the area of LGBTI health?
5. Where can I find additional resources on health and human rights for LGBTI persons?
6. What are key terms related to health and human rights for LGBTI persons?



# I. HOW IS HEALTH A HUMAN RIGHTS ISSUE FOR LGBTI PERSONS?

## What are the issues and how are they human rights issues?

There is a plethora of issues that affect the health of lesbian, gay, bisexual, transgender and intersex (LGBTI) persons, many of which are issues relating to human rights. Around the world and in all societies, LGBTI persons face discrimination and marginalisation which puts them at risk of not being able to attain the highest attainable standard of health. This chapter does not intend to be comprehensive in its coverage of the human rights issues that affect the health of LGBTI persons – there are simply too many; however, it will provide the reader with an overview and a starting point to understand some of the human rights issues affecting LGBTI persons' health.<sup>1</sup> The chapter also intends to leave the reader with an understanding that a respect for human rights, which apply equally to all people, can be a strong driver for effecting positive change in health issues of LGBTI persons.

## Problems posed by heteronormativity

As a starting point, it is important to understand the problems that are posed by heteronormativity. Most societies are structured around two binary genders, male and female, and only one 'normal' sexual orientation, heterosexual. Medical practitioners, health care workers, policy-makers, and educators often fail to talk about, or even consider, those who fall outside of this norm. LGBTI persons are those who are not heterosexual (sexual orientation) and/or those whose identity is not gender conforming by societal norms (gender identity). LGBTI refers to gay, lesbian and/or bisexual persons (sexual orientation) and transgender or intersex persons (gender identity). When the issues of sexual orientation or gender identity are considered, often little or no thought is given to how the right to health of these individuals could be better protected, or is being violated. This invisibility, and associated isolation and marginalization, can have tragic consequences for the health and wellbeing of many members of LGBTI communities.

<sup>1</sup> See, Mahon C, "Sexual Orientation, Gender Identity and the Right to Health" in Clapham C et al, eds., *Realizing the Right to Health*, Swiss Human Rights Book, Vol. 3 (Zurich: Rüffer & Rub, 2009). [http://www.swisshumanrightsbook.com/etc/medialib/downloads/edazen/topics/human/srbook.Par.0065.File.tmp/14\\_453\\_Mahon.pdf](http://www.swisshumanrightsbook.com/etc/medialib/downloads/edazen/topics/human/srbook.Par.0065.File.tmp/14_453_Mahon.pdf).

LGBTI people have long been the victims of violations of their human rights. They have been subjected to direct violations, whereby their physical or mental health is compromised because of their actual or perceived sexual orientation<sup>2</sup> or gender identity<sup>3</sup>. Lesbians, gays, bisexuals, transgender and intersex persons have been attacked,<sup>4</sup> arrested,<sup>5</sup> tortured,<sup>6</sup> killed,<sup>7</sup> sentenced to death,<sup>8</sup> committed to medical or psychiatric institutions and treated with ‘aversion therapy’ including electroshock therapy or forced rape.<sup>9</sup> Intersex individuals, especially those with visibly atypical anatomy, have been subjected to surgery against their will, for example, to ‘correct’ their ‘ambiguous genitalia’.<sup>10</sup> LGBTI persons are also indirectly victimized through failures to recognize and consider this diverse group as healthcare recipients with specific needs resulting in denial of access to the full enjoyment of their right to the highest attainable standard of health.

LGBTI persons experience frequent human rights violations based solely upon their LGBTI status, which has major impacts upon the health of LGBTI persons. For example, LGBTI persons often suffer violations of the right to privacy, the right to education, the right to family life, even housing and employment rights, particularly when they are discriminated against on the grounds of their sexual orientation or gender identity.<sup>11</sup>

This situation is an unacceptable affront to human dignity, particularly given the startling statistics that have been well known for many years: LGBTI people, especially LGBTI youth, are highly susceptible to poor

- 2 This chapter draws on the definition of ‘sexual orientation’ used in the Yogyakarta Principles: “‘sexual orientation’ ... refer[s] to each person’s capacity for profound emotional, affectional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender.” *Yogyakarta Principles: The Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity* (March 2007). <http://www.yogyakartaprinciples.org/>.
- 3 This chapter draws on the definition of ‘gender identity’ used in the Yogyakarta Principles: “‘gender identity’ ... refer[s] to each person’s deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms.” *Yogyakarta Principles: The Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity* (March 2007). <http://www.yogyakartaprinciples.org/>.
- 4 See, e.g., UN Committee Against Torture, *Conclusions and recommendations of the Committee against Torture: Venezuela*, CAT/C/CR/29/2 (December 23, 2002) at para. 10(d).
- 5 UN Commission on Human Rights, *Question of the Human Rights of All Persons Subjected to any Form of Detention or Imprisonment, In Particular: Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment: Report of the Special Rapporteur, Mr. Nigel S. Rodley, submitted pursuant to Commission on Human Rights resolution 1992/32*, E/CN.4/1995/34 (January 12, 1995).
- 6 See, UN Committee Against Torture, *Conclusions and recommendations of the Committee against Torture: Argentina*, CAT/C/CR/33/1 (December 10, 2004) at para. 6(g); UN Committee Against Torture, *Conclusions and recommendations of the Committee against Torture: Egypt*, CAT/C/CR/29/4 (December 23, 2002) at para. 5(e).
- 7 UN Commission on Human Rights, *Internally displaced persons: Report of the Representative of the Secretary-General, Mr. Francis Deng, submitted pursuant to Commission on Human Rights resolution 1993/95: Addendum: Profiles in displacement: Colombia*, E/CN.4/1995/50/Add.1 (October 3, 1994); UN Commission on Human Rights, *Joint report of the Special Rapporteur on the question of torture, Mr. Nigel S. Rodley, and the Special Rapporteur on extrajudicial, summary or arbitrary executions, Mr. Bacre Waly Ndiaye, submitted pursuant to Commission on Human Rights resolutions 1994/37 and 1994/82: Visit by the Special Rapporteurs to the Republic of Colombia from 17 to 26 October 1994*, E/CN.4/1995/111 (January 16, 1995).
- 8 UN Commission on Human Rights, *Report on the situation of human rights in the Islamic Republic of Iran, prepared by the Special Representative of the Commission on Human Rights, Mr. Maurice Copithorne (Canada), pursuant to Commission resolution 1995/68 of 8 March 1995 and Economic and Social Council decision 1995/279 of 25 July 1995*, E/CN.4/1996/59 (March 21, 1996).
- 9 See, UN Commission on Human Rights, *The right of everyone to the enjoyment of the highest attainable standard of physical and mental health: Report of the Special Rapporteur, Paul Hunt*, E/CN.4/2004/49 (February 16, 2004) at para. 38; UN General Assembly, *Report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment*, A/56/156 (July 3, 2001); UN Commission on Human Rights, *Torture and other cruel, inhuman or degrading treatment or punishment: Report of the Special Rapporteur, Theo van Boven*, E/CN.4/2004/56 (December 23, 2003); International Commission of Jurists, *Sexual Orientation and Gender Identity in Human Rights Law: References to Jurisprudence and Doctrine of the United Nations Human Rights System* (July 2007). <http://www.refworld.org/docid/4ad5b83a2.html>; Amnesty International, *Crimes of Hate, Conspiracy of Silence: Torture and Ill-Treatment based on Sexual Identity*, AI Index ACT 40/016/2001 (2001). <http://www.amnesty.org/en/library/info/ACT40/016/2001>; Amnesty International, *Breaking the Silence: Human Rights Violations Based on Sexual Orientation*, (London: Amnesty International Publications, 1994); Human Rights Watch, *Hated to Death: Homophobia, Violence and Jamaica’s HIV/AIDS Epidemic* (November 2004). <http://hrw.org/reports/2004/jamaica1104/jamaica1104.pdf>; Human Rights Watch and The International Gay and Lesbian Human Rights Commission, *More Than A Name: State-Sponsored Homophobia and its Consequences in Southern Africa* (2003). <http://www.iglhrc.org/sites/default/files/160-1.pdf>.
- 10 O’Flaherty M and Fisher J, “Sexual Orientation, Gender Identity and International Human Rights Law: Contextualising the Yogyakarta Principles,” 8(2) *Human Rights Law Review* (2008) 207-248, at 213; Intersex Society of North America, “Frequently Asked Questions,” <http://www.isna.org/faq/>; Morris E, “The self I will never know,” 364 *New Internationalist* (2004). <http://newint.org/features/2004/02/01/self/>.
- 11 Amnesty International, *Breaking the Silence: Human Rights Violations Based on Sexual Orientation*, (London: Amnesty International Publications, 1994).

health and health risks.<sup>12</sup> Male teenagers who identify as gay are 2-3 times more likely than their peers to attempt suicide (although some studies put this figure as high as 6-30 times more likely<sup>13</sup>), and suicide attempts amongst LGBTI youth in general are reportedly 3-7 times higher than for heterosexual youth.<sup>14</sup> For these young people, family or social pressure to conform to the heterosexual norm makes them highly susceptible to mental health problems and places their personal safety at risk. The rate of suicide and suicide attempts amongst LGBTI adults is also higher than in the heterosexual community.

Studies have also shown that ‘sexual minorities’ have a higher rate of other mental health problems including depression, bipolar disorder, panic attacks, as well as substance abuse including tobacco, alcohol and drug addictions and other ‘unhealthy behaviours’ such as high-risk/unsafe sex, and higher infection rates for HIV/AIDS and other sexually transmitted diseases.<sup>15</sup> For example, it has been shown lesbian women are more likely to smoke, abuse alcohol, weigh more, and suffer stress, than heterosexual women, placing them in a higher risk category for heart disease, stroke, cervical and other forms of cancer.<sup>16</sup> Also, lesbians usually have fewer pregnancies and live births than their heterosexual counterparts which results in greater hormone exposure and increases their risk of breast, uterine and ovarian cancer.<sup>17</sup>

## What are LGBTI health rights?

This section reviews some of the human rights that, when respected, can help protect LGBTI persons’ health. It looks at the right to the highest attainable standard of health, the right to be free from discrimination, the right to life and security of the person, and the right to be free from torture or cruel, inhuman or degrading treatment. As noted above, there are many other rights that, when violated can have major impacts on the health of LGBTI persons. Section two of this chapter sets out many more human rights and provides examples of violations of each human right.

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- 12 See, inter alia, Kroll and Warneke, *The Dynamics of Sexual Orientation and Adolescent Suicide: A Comprehensive Review and Development Perspective* (Calgary: University of Calgary, 1995).
- 13 White R, “Growing Up as a Gay Young Person in Ireland – So What’s the Story?” in Rainbow Project, and “Carers are Ignoring Gay Teens,” *Irish News*, 5 June 1988, both cited in Northern Ireland Human Rights Commission, *Enhancing the Rights of Lesbian, Gay and Bisexual People in Northern Ireland* (August 2001). <http://www.nihrc.org/documents/research-and-investigations/lgbt/enhancing-right-lesbian-gay-people-northern-ireland-2001.pdf>.
- 14 See, Russell ST and Joyner K, “Adolescent Sexual Orientation and Suicide Risk: Evidence From a National Study,” 91 *American Journal of Public Health* (2001) 1276; Arriola ER, “The Penalties for Puppy Love: Institutionalized Violence Against Lesbian, Gay, Bisexual and Transgendered Youth,” 1 *Journal of Gender, Race and Justice* (1998) 429, at 439-47; Paul J et al, “Suicide Attempts Among Gay and Bisexual Men: Lifetime Prevalence and Antecedents,” 92 *American Journal of Public Health* (2002) 1338; Boucai MD, “Legal Remedy for Homophobia: Finding a Cure in the International Right to Health,” 6 *Georgia Journal of Gender and Law* 21 (2005).
- 15 Boucai MD, “Legal Remedy for Homophobia: Finding a Cure in the International Right to Health,” 6 *Georgia Journal of Gender and Law* 21 (2005).
- 16 University of Washington Women’s Health, “Lesbian Health: Getting the care you deserve.” <http://depts.washington.edu/uwcoe/healthtopics/lesbian-health.html>.
- 17 Mahon C, “Sexual Orientation, Gender Identity and the Right to Health” in Clapham C et al, eds., *Realizing the Right to Health*, Swiss Human Rights Book, Vol. 3 (Zurich: Rüffer & Rub, 2009). [http://www.swisshumanrightsbook.com/etc/medialib/downloads/edazen/topics/human/srbook.Par.0065.File.tmp/14\\_453\\_Mahon.pdf](http://www.swisshumanrightsbook.com/etc/medialib/downloads/edazen/topics/human/srbook.Par.0065.File.tmp/14_453_Mahon.pdf). See also, Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* (2011).

## The right to the highest attainable standard of health

The human right with the most obvious links to LGBTI health is the right to the enjoyment of the highest attainable standard of physical and mental health (often referred to simply as ‘the right to health’). The right to health is protected under international human rights law through article 25 of the Universal Declaration of Human Rights (UDHR), article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), and other international and regional treaties and conventions.<sup>18</sup> All of these international legal protections apply to people of all sexual orientations and gender identities because the right to health contained in the UDHR and ICESCR is “the right of everyone to the highest attainable standard of physical and mental health,” not just the right of heterosexual males and females.<sup>19</sup>

The United Nations Committee on Economic, Social and Cultural Rights (CESCR) explains in General Comment No. 14 on the right to the highest attainable standard of health, that discrimination on any basis, including on the basis of sex and sexual orientation, is contrary to article 2(2) (non-discrimination) and article 3 (equal rights of men and women) of ICESCR.<sup>20</sup> CESCR later confirms in General Comment No. 20, that the “other status” listed in ICESCR article 2(2) on non-discrimination, includes sexual orientation and gender identity.<sup>21</sup> Therefore ICESCR prohibits discrimination on the basis of sexual orientation or gender identity. This is consistent with the case law of the United Nations Human Rights Committee, which decided in the matter of *Toonen v Australia*, that the prohibition against discrimination on the basis of ‘sex’ includes discrimination on the basis of sexual orientation.<sup>22</sup> The European Court of Human Rights has also confirmed that discrimination in treatment due to a person’s sexual orientation is the “embodi[-ment of] a predisposed bias on the part of a heterosexual majority against a homosexual minority, [and] these negative attitudes cannot of themselves be considered by the Court to amount to sufficient justification for the differential treatment any more than similar negative attitudes towards those of a different race, origin or colour”.<sup>23</sup>

On March 26, 2007, The Yogyakarta Principles on the Application of Human Rights Law in Relation to Sexual Orientation and Gender Identity (the Yogyakarta Principles) were launched. They comprehensively examine the human rights for all persons, regardless of sexual orientation or gender identity and identify the relevant obligations under international human rights law. The preamble states that the Yogyakarta Principles are based on the premise that:

*... international human rights law affirms that all persons, regardless of sexual orientation or gender identity, are entitled to the full enjoyment of all human rights, [and] that the application of existing human rights entitlements should take account of the specific situations and experiences of people of diverse sexual orientations and gender identities.<sup>24</sup>*

18 Including, inter alia, the Convention on the Rights of the Child (article 24); the International Convention on the Elimination of All Forms of Racial Discrimination (article 24); the International Convention on the Elimination of all Forms of Discrimination Against Women (article 11); the Convention on the Rights of Persons with Disabilities (article 25); the African Charter on Human and Peoples’ Rights (article 16); the African Charter on the Rights and Welfare of the Child (article 14); the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa; the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (the Protocol of San Salvador) (article 10); the Arab Charter on Human Rights (article 39); and the European Social Charter (common article 11).

19 International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 12(1), emphasis added. See also, International Commission of Jurists (ICJ), *Sexual Orientation and Gender Identity: A Practitioner’s Guide* (Geneva: ICJ, 2008), in particular ‘Chapter 8: Right to Health’; and Heinze E, *Sexual Orientation – A Human Right: An Essay on International Human Rights Law* (Dordrecht: Martinus Nijhoff Publishers, 2005).

20 Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14, E/C.12/2000/4 (August 11, 2000).

21 Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 20*, E/C.12/GC/20 (July 2, 2009).

22 UN Human Rights Committee, *Toonen v Australia*, Communication No. 488/1992, CCPR/C/50/D/488/1992 (March 31, 1994).

23 *Case of S.L. v Austria*, Application No. 45330/99 (January 1, 2003), at para. 44. <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-60877>. This case concerns the differing age of consent for homosexuals and heterosexuals.

24 International Commission of Jurists (ICJ), *Yogyakarta Principles: The Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity* (March 2007), preambular paragraph 6. <http://www.yogyakartaprinciples.org/>.

The Yogyakarta Principles were signed by 29 international human rights experts, after a draft process and workshop organized by the International Commission of Jurists and the International Service for Human Rights.

Principles 17 and 18 address the right to the highest attainable standard of health and protection from medical abuses. Principle 17 of the Yogyakarta Principles states: “Everyone has the right to the highest attainable standard of physical and mental health, without discrimination on the basis of sexual orientation or gender identity. Sexual and reproductive health is a fundamental aspect of this right.” This Principle details nine aspects of state obligations related to this right, including:

1. the duty to take legislative and other measures to ensure the right to health and access to healthcare;
2. the treatment of medical records with confidentiality;
3. the design and development of healthcare resources and programmes to improve the health status of LGBTI people and address discrimination and prejudice;
4. the need for informed and empowered decisions regarding medical treatment and care;
5. non-discrimination and respect for the diversity of sexual orientations and gender identities in sexual health, education, prevention, care and treatment, including recognition of next of kin;
6. facilitating access to gender reassignment treatments; and
7. adopting policy-making and education and training programmes for healthcare workers to improve treatment for LGBTI people.

Principle 18, which addresses the need for LGBTI persons to be protected from medical abuses, states:

*No person may be forced to undergo any form of medical or psychological treatment, procedure, testing, or be confined to a medical facility, based on sexual orientation or gender identity. Notwithstanding any classifications to the contrary, a person’s sexual orientation and gender identity are not, in and of themselves, medical conditions and are not to be treated, cured or suppressed.*

Principle 18 is broken down into a set of five obligations for states, including:

1. taking the necessary legislative and other measures to ensure protection against harmful medical practices, including the irreversible alteration of a child’s body through attempts to impose a gender identity;
2. establishing child protection mechanisms to reduce risk of medical abuse;
3. ensuring LGBTI people are not used to unethically or involuntarily test medical procedures or conduct research, and reversing funding programmes that would enable such abuses; and
4. ensuring medical and psychological treatment does not treat sexual orientation and gender identity as a pathology.

These provisions in the Yogyakarta Principles provide guidance on how international human rights law can be applied in the specific context of respecting, protecting and promoting the right to health for LGBTI persons.

### ***Violations of the right to the highest attainable standard of health***

The United Nations Special Rapporteur on the right to the highest attainable standard of physical and mental health explained in his 2004 report:

*The legal prohibition of same-sex relations in many countries, in conjunction with a widespread lack of support or protection for sexual minorities against violence and discrimination, impedes the enjoyment of sexual and reproductive health by many people with lesbian, gay, bisexual, or transgender identities or conduct.*<sup>25</sup>

It is not only sexual and reproductive health that is impeded – all forms of physical and mental health can be affected by discriminatory policies and practices, and the homophobia or heterosexism of society in general and medical practitioners in particular.

## **Freedom from discrimination**

LGBTI persons experience multiple forms and manifestations of discrimination. For the purpose of illustrating the issue of discrimination, this section will examine homophobia as a form of discrimination that affects the health of LGBTI persons.

LGBTI student activists have described some of the problems they see resulting from heterosexism:<sup>26</sup>

*“Once the heterosexist assumption is made, many gay men feel the necessity to maintain it. If you can’t talk to your doctor about who you have sex with, you won’t get the information you need ...”*<sup>27</sup>

*“One health challenge is that providers don’t necessarily know the sexual orientation of their patients. This can prevent them from asking certain questions, probing for certain risk behaviors, or looking for indications of a particular illness – which does a disservice to their patients ...”*<sup>28</sup>

*“There’s another potential barrier to health care ... regarding “coming out:” Is your provider friendly? How do you know that what you say to them will be private? What are the implications of whether or not you have privacy? ... It’s a greater risk for youth because if you come out to your doctors, are they going to tell your parents or the people you’re living with? With teens coming out at a younger age, the risk of homelessness has skyrocketed for adolescents whose parents aren’t ready for their coming out even if the person is young. That’s a major health concern right there.”*<sup>29</sup>

25 UN Commission on Human Rights, *The right of everyone to the enjoyment of the highest attainable standard of physical and mental health: Report of the Special Rapporteur, Paul Hunt*, E/CN.4/2004/49 (February 16, 2004) at para. 38.

26 Heterosexism refers to the presumption that everyone is heterosexual and that opposite-sex attractions and relationships are the norm.

27 Danni (interview subject), “Sexual Orientation and Other Sexual Minorities,” in *Healthy Maine 2010: Opportunity For All*, at 62. <http://www.maine.gov/dhhs/boh/files/hm2010/oppforall/b1osexor.pdf>.

28 Galena R (interview subject), *Ibid.* at 63.

29 Burns P (interview subject), *Ibid.* at 62.



Sharing your sexual orientation or gender identity with others, by ‘coming out’, is important for positive mental health. A society that discourages coming out, discourages recognition of each individual’s worth and dignity. It also fosters a culture where, from an early age, LGBTI people are unlikely to be able to properly access the full range of health services and health information that should be available to them, because traditional views about sexuality create obstacles to the provision of health services.<sup>30</sup> Researchers have found that in health care situations LGBTI patients suffer “ostracism, invasive questioning, rough physical handling, derogatory comments, breaches of confidentiality, shock, embarrassment, unfriendliness, pity, condescension, and fear”.<sup>31</sup> They “respond to this mistreatment by delaying medical care or risking potential misdiagnosis by hiding their sexual orientation.”<sup>32</sup> Homophobia, ignorance and fear are not just impediments to accessing healthcare, but also to research,<sup>33</sup> further perpetuating the cycle of mistreatment.

Homophobic societies also inhibit education and advocacy about safe sex and other health matters. In places where homosexual activities are criminalized, HIV/AIDS education and other forms of preventive health care that should be tailored to LGBTI communities are suppressed. For example, non-governmental organizations (NGOs) such as Human Rights Watch have reported that the crackdown on lesbians and gays in Uganda, prompted by “state homophobia”, is “undermining Uganda’s efforts to combat the spread of HIV/AIDS”.<sup>34</sup> Amnesty International reports that the arrest, detention, and compulsory testing of men suspected of having HIV in Egypt “not only violates the most basic rights of people living with HIV ... [i]t also threatens public health, by making it dangerous for anyone to seek information about HIV prevention or treatment.”<sup>35</sup> Marginalizing LGBTI people undermines public health initiatives, leaving this significant sector of the community underserved and often afraid to seek treatment, even if they could, due to stigmatization or criminalization.<sup>36</sup> Other prejudices, such as those associated with HIV/AIDS, may reinforce and exacerbate discrimination on the grounds of sexual orientation or gender identity, or vice versa, making it less likely that those in need access health services, even if such services are available.<sup>37</sup>

30 UN Commission on Human Rights, The right of everyone to the enjoyment of the highest attainable standard of physical and mental health: Report of the Special Rapporteur, Paul Hunt, E/CN.4/2004/49 (February 16, 2004) at para. 14.

31 Stevens PE and Hall JM, as quoted in Gartner N, “Articulating Lesbian Human Rights: The Creation of a Convention on the Elimination of All Forms of Discrimination Against Lesbians,” 14 *UCLA Women’s Law Journal* (2005) 61, at 82-3. See also, Boucai MD, “Legal Remedy for Homophobia: Finding a Cure in the International Right to Health,” 6 *Georgia Journal of Gender and Law* 21 (2005), at 32.

32 Stevens PE and Hall JM, as quoted in Gartner N, “Articulating Lesbian Human Rights: The Creation of a Convention on the Elimination of All Forms of Discrimination Against Lesbians,” 14 *UCLA Women’s Law Journal* (2005) 61, at 83.

33 Dean L, et al., ‘Lesbian, Gay, Bisexual and Transgender Health: Findings and Concerns’ 4 *Journal of the Gay and Lesbian Medical Association* (2000) 101. See also, Boucai MD, “Legal Remedy for Homophobia: Finding a Cure in the International Right to Health,” 6 *Georgia Journal of Gender and Law* 21 (2005).

34 Human Rights Watch, Uganda: State Homophobia Threatens Health and Human Rights: Government Persecution Contributing to HIV Pandemic (August 23, 2007). <http://hrw.org/english/docs/2007/08/22/uganda16729.htm>.

35 Amnesty International, Egypt: Spreading Crackdown on HIV Endangers Public Health: Rights Violations Drive Those in Need Underground (February 19, 2008). <http://www.hrw.org/news/2008/02/14/egypt-spreading-crackdown-hiv-endangers-public-health>.

36 Wilets J, “Using International Law to Vindicate the Civil Rights of Gays and Lesbians in United States Courts,” 27 *Columbia Human Rights Law Review* (1995) 33, 34; Boucai MD, “Legal Remedy for Homophobia: Finding a Cure in the International Right to Health,” 6 *Georgia Journal of Gender and Law* 21 (2005).

37 UN Commission on Human Rights, The right of everyone to the enjoyment of the highest attainable standard of physical and mental health: Report of the Special Rapporteur, Paul Hunt, E/CN.4/2004/49 (February 16, 2004) at para. 35.



## Right to life and security of the person

LGBTI persons are vulnerable to targeted violence on the basis of their sexual orientation or gender identity. Five countries impose the death penalty for same-sex conduct. This is a violation of Article 6 of the ICCPR, which states that a sentence of death may be imposed only for the most serious crimes. The United Nations Office of the High Commissioner for Human Rights (OHCHR) has stated that same-sex conduct does not qualify as a most serious crimes, thus it should not be penalised by death.<sup>38</sup>

Violence against LGBTI persons is also often perpetrated by non-state actors. Documentation of violence against LGBTI persons because of their LGBTI status has included extrajudicial killings, killings of transgender individuals, “honour killings”<sup>39</sup> perpetrated by family or community members, rape and sexual violence and other hate-motivated violence. For example, the Trans Murder Monitoring Project reported in March 2013 that there have been “1,123 reported killings of trans people in 57 countries worldwide from January 1st 2008 to December 31st 2012.”<sup>40</sup>

With respect to sexual violence, lesbians, bisexual women, and transgender peoples’ risk of rape may be even higher than the risk for heterosexual women because they may be special targets for punitive or corrective rape. Corrective rape is “a phenomenon in which men rape people they presume or know to be lesbians in order to ‘convert’ them to heterosexuality,” and it is a common form of sexual violence against LGBTI women.<sup>41</sup>

Violence on the basis of sexual orientation or gender identity is usually hate-motivated.<sup>42</sup> Under international law, states are obligated to protect individuals from violence and to prosecute those who perpetrate violence against individuals. The ICCPR provides every human being the inherent right to life. Under the ICCPR, State Parties are obligated to protect the right to life (Article 6). The ICCPR also provides everyone the right to liberty and security of person (Article 9). This includes the obligation to investigate all hate crimes and incidence of violence against an individual and to punish each perpetrator.

## Freedom from torture or cruel, inhuman or degrading treatment

Actual or perceived LGBTI persons are subjected to torture in many countries, often perpetrated because of stigma associated with LGBTI persons. The OHCHR explains that sexual violence “may constitute torture when it is carried out by, or at the instigation of, or with the consent or acquiescence of public officials.”<sup>43</sup> Police and prison guards are often perpetrators of torture against LGBTI persons or are complicit in permitting torture to be perpetrated by others.

38 See, UN Office of the High Commissioner for Human Rights, *Born Free and Equal: Sexual Orientation and Gender Identity in International Human Rights Law*, HR/PUB/12/06 (2012) at 34. <http://www.ohchr.org/Documents/Publications/BornFreeAndEqualLowRes.pdf>.

39 “Honour killings” are murders undertaken by a family or community against an individual who has brought shame on a family through their actions. The murders are thought to purge the family of the dishonor brought upon them by the individuals.

40 TGEU, “More than 1100 murdered trans people reported: TGEU Press Release” (March 2013), [http://www.tgeu.org/More\\_than\\_1100\\_trans\\_murders\\_reported\\_in\\_5\\_years\\_TGEU\\_Press\\_Release](http://www.tgeu.org/More_than_1100_trans_murders_reported_in_5_years_TGEU_Press_Release).

41 Human Rights Watch, “We’ll Show You You’re a Woman”: *Violence and Discrimination against Black Lesbians and Transgender Men in South Africa* (2011). <http://www.hrw.org/sites/default/files/reports/southafrica1211.pdf>.

42 UN Human Rights Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, A/HRC/14/20* (April 27, 2010). <http://www2.ohchr.org/english/bodies/hrcouncil/docs/14session/A.HRC.14.20.pdf>; UN Office of the High Commissioner for Human Rights, *Born Free and Equal: Sexual Orientation and Gender Identity in International Human Rights Law*, HR/PUB/12/06 (2012). <http://www.ohchr.org/Documents/Publications/BornFreeAndEqualLowRes.pdf>.

43 UN Office of the High Commissioner for Human Rights, *Born Free and Equal: Sexual Orientation and Gender Identity in International Human Rights Law*, HR/PUB/12/06 (2012). <http://www.ohchr.org/Documents/Publications/BornFreeAndEqualLowRes.pdf> [quoting UN General Assembly, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/7/3 (Jan. 15, 2008)].

Another form of documented torture against LGBTI persons is the use of non-consensual anal or vaginal examinations on suspected LGBTI persons in attempt to obtain physical evidence of suspected sexual behavior. For example, anal and vaginal examinations, dubbed “Tests of Shame” in Lebanon are used to investigate a suspect’s sexual behaviour. These tests constitute a form of torture and—as utilized by law enforcement and the courts—are humiliating and degrading acts.<sup>44</sup> Likewise, in Egypt in 2002, Egyptian authorities used forensic anal examinations on 52 men who were arrested for “debauchery” in a nightclub.<sup>45</sup> These practices constitute torture and exacerbate discrimination and violence against LGBTI individuals.

The Committee against Torture (CAT) explains that “[t]he protection of certain minority or marginalized individuals or populations especially at risk of torture is a part of the obligation to prevent torture or ill-treatment.”<sup>46</sup> The CAT goes on to explain that “insofar as the obligations arising under the Convention are concerned, their laws are in practice applied to all persons, regardless of ... sexual orientation.”<sup>47</sup> The CAT further explains that ensuring the protection of marginalized groups who are especially at risk of torture includes “fully prosecuting and punishing all acts of violence and abuse against these individuals and ensuring implementation of other positive measures of prevention and protection....”<sup>48</sup>

The Special Rapporteur on torture explains in a recent report with regard to lesbian, gay, bisexual, transgender and intersex persons that:

*There is an abundance of accounts and testimonies of persons being denied medical treatment, subjected to verbal abuse and public humiliation, psychiatric evaluation, a variety of forced procedures such as sterilization, State-sponsored forcible anal examinations for the prosecution of suspected homosexual activities, and invasive virginity examinations conducted by health-care providers, hormone therapy and genital normalizing surgeries under the guise of so called “reparative therapies”. These procedures are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma.*<sup>49</sup>

The Special Rapporteur further explains that many intersex and transgender persons are subjected to involuntary procedures. Often these procedures are conducted only “because [the individuals] fail to conform to socially constructed gender expectations”<sup>50</sup> and that, “[i]ndeed, discrimination on grounds of sexual orientation or gender identity may often contribute to the process of the dehumanization of the victim, which is often a necessary condition for torture and ill-treatment to take place.”<sup>51</sup> For example, children with atypical sex characteristics are often subjected to “irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, ‘in an attempt to fix their sex’.”<sup>52</sup> While transgender persons are required to undergo unwanted sterilization surgeries, ‘gender-confirming surgery,’ or ‘gender reassignment surgery,’ “as a prerequisite to enjoy legal recognition of their preferred gender.”<sup>53</sup>

44 Human Rights Watch, *Lebanon: Stop “Tests of Shame”: Authorities Order Anal Examinations of Men Charged with Homosexuality* (August 10, 2012). <http://www.hrw.org/news/2012/08/10/lebanon-stop-tests-shame>.

45 Human Rights Watch, *In a Time of Torture: The Assault on Justice in Egypt’s Crackdown on Homosexual Conduct* (March 1, 2004). <http://www.hrw.org/reports/2004/02/29/time-torture-o>.

46 UN Committee against Torture, *General Comment 2, CAT/C/GC/2* (January 24, 2008), para. 21.

47 Ibid.

48 Ibid.

49 Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53* (Feb 2013), at para. 76. [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

50 Ibid. at para. 77, 78.

51 Ibid. at para. 79.

52 Ibid. at para. 77.

53 Ibid. at para. 78.

## What are human rights-based approaches for upholding the health rights of LGBTI persons?

This section provides some examples of human rights-based approaches that can be effective in upholding the health rights of LGBTI persons.

### Allow for LGBTI persons to affirm their gender identity in state documents

Allowing people to affirm their gender identity in state documents and other administrative procedures is necessary to achieve the highest attainable standard of health. Upholding a right to privacy in relation to past and present gender identity, and the ability to change legal identity to protect this privacy, also helps to ensure that LGBTI persons are less likely to be subjected to unlawful discrimination, harassment, and psychological harm. The ability to affirm ones' gender identity in state documents has been questioned in a number of courts, including the European Court of Human Rights. In a variety of cases, the Court has addressed issues that are highly relevant to the enjoyment of the right to the highest attainable standard of health for LGBTI persons, although this has usually been achieved through applying the right to privacy. For example, in the cases of *Goodwin v United Kingdom*<sup>54</sup> and *I. v United Kingdom*,<sup>55</sup> the Court ruled that the United Kingdom (UK) Government's refusal to recognize the post-operative genders of two transsexual women was discriminatory and a violation of their right to privacy and right to a family.

### The Right to Receive Appropriate, Gender-Affirming Health Care

Another aspect of LGBTI health is the right to receive appropriate, gender-affirming health care that is adequately provided for by the State. This includes the freedom to change one's gender through the use of medical procedures. It is also important when considering what the content of the right to health means for transgender persons. The European Court of Human Rights describes a case about a female-to-male gender re-assignment patient unable to complete his transformation because "there [was] no law regulating full gender reassignment surgery."<sup>56</sup> While the State had passed a Gender Reassignment Bill entitling transsexuals to have civil documents changed after full gender reassignment, there was no enactment of the Bill because no "legal instrument regulated the conditions and procedure for gender reassignment."<sup>57</sup> While the patient, having undergone partial surgery, could not access full gender reassignment surgery and therefore, could not change civil-status documents to reflect his change of gender. The patient alleged that:

*[H]is continuing inability to complete gender-reassignment surgery left him with a permanent feeling of personal inadequacy and an inability to accept his body, leading to great anguish and frustration. Furthermore, due to the lack of recognition of his perceived, albeit pre-operative, identity, the applicant constantly faced anxiety, fear, embarrassment and humiliation in his daily life. He has had to submit to severe hostility and taunts in the light of the general public's strong opposition, rooted in traditional Catholicism, to gender disorders. Consequently, he has had to follow an almost underground life-style, avoiding situations in which he might have to disclose his original identity, particularly when having to provide his personal code. This has left him in a permanent state of depression with suicidal tendencies.<sup>58</sup>*

54 *Case of Christine Goodwin v. the United Kingdom*, Application No. 28957/95 (July 11, 2002). <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-60596>.

55 *Case of I. v. the United Kingdom*, Application No. 25680/94 (July 11, 2002). <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-60595>.

56 *Case of L. v Lithuania*, Application No. 27527/03 (September 11, 2007). <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-82243>.

57 *Ibid.*

58 *Ibid.*

The Court ruled that the lack of implementing legislation violated the applicant's right to private life. Indeed, the Court ruled that it was necessary for a state, in this instance Lithuania, to make changes to their civil code in order to protect the right to full gender-reassignment surgery, and allocate budgetary measures to facilitate the fulfilment of this right.<sup>59</sup>

Also, European Court of Human Rights has addressed the issue of providing funding for transition-related procedures. The European Court of Human Rights said that freedom to define one's own gender identity is "one of the most basic essentials of self-determination."<sup>60</sup> This belief was enumerated in a recent case from 2003, where the Court ruled that Germany had failed to respect the freedom to define one's gender identity (part of the right to privacy) when its civil courts refused a woman's appeal against her health insurance company and its rejection of her claim for reimbursement of the costs of her sex-reassignment surgery.<sup>61</sup> This could be seen as part of a positive obligation to facilitate the self-determination of gender identity, including through the provision and funding of relevant health care procedures.

### Require Full and Informed Consent for Medical Procedures

LGBTI persons are vulnerable to undergoing coerced medical procedures. This is particularly true for intersex and transgender persons, for whom obtaining gender-correct identification is predicated on undergoing specific medical procedures. The Special Rapporteur on torture recently recommended, regarding LGBTI persons specifically, that all States "repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, "reparativetherapies" or "conversion therapies", when enforced or administered without the free and informed consent of the person concerned."<sup>62</sup> The right to informed consent protects the right of the patient to be involved in medical decision-making and requires a voluntary and sufficiently informed decision.<sup>63</sup>

### Take Into Account LGBTI Persons in Health Policy Setting

Another way in which LGBTI persons' health can be impacted is through a failure to adequately take into account their specific needs, and tailor health care systems, including training for health care practitioners, to be more sensitive to the concerns of the LGBTI community. For example, some health providers and health systems focus on treating the identity of the patient rather than their body. Also, gays and lesbians are "overlooked and underserved" when it comes to their unique health care needs.<sup>64</sup> For example, the sexual and reproductive health needs, including fertility, of same-sex practicing couples is often overlooked or misunderstood. Likewise, transgender persons face many obstacles in accessing 'gender-appropriate services,'<sup>65</sup> which may be complicated when insurance refuses to pay for gender-specific services for transgender or intersex patients. Health policy makers simply fail to prioritise this particular group of consumers of health services, along with other LGBTI people.

59 *Case of L. v Lithuania*, Application No. 27527/03 (September 11, 2007). <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-82243>.

60 *Case of Van Kück v. Germany*, Application No. 35968/97 (June 12, 2003). <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-61142>.

61 *Ibid.*

62 Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb 2013), at para. 88. [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

63 UN General Assembly, *Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (August 10, 2009).

64 Gartner N, "Articulating Lesbian Human Rights: The Creation of a Convention on the Elimination of All Forms of Discrimination Against Lesbians," 14 *UCLA Women's Law Journal* (2005) 61.

65 O'Flaherty M and Fisher J, "Sexual Orientation, Gender Identity and International Human Rights Law: Contextualising the Yogyakarta Principles," 8(2) *Human Rights Law Review* (2008): 207-248, at 211.

While national health systems are often poorly designed to serve the needs of ‘sexual minorities’, likewise international health care programming is not effectively targeting these groups in need. For example, in 2007 the International Gay and Lesbian Human Rights Commission (IGLHRC) published a study that analysed how the international funding community, governments, and NGOs are failing LGBTI people because HIV/AIDS programming is not addressing same-sex practicing people, and only leads to denying further LGBTI patients’ access to effective HIV prevention, counselling and testing, treatment, and care.<sup>66</sup> “Moving the mountain” is how the group has described the epic struggle to get HIV programmers and policymakers to address how anti-gay discrimination fuels the HIV/AIDS crisis in Africa and elsewhere.<sup>67</sup>

The failure to protect health rights for LGBTI people is as much a failure of human rights practitioners and the human rights system, as it is a failure of health practitioners and health systems, because “[h]uman rights law has developed ... while keeping the issues of sexuality firmly in the closet.”<sup>68</sup> Even as human rights law has developed, it has continued to marginalize LGBTI people and it has failed to adequately integrate the rights of LGBTI people.<sup>69</sup>

### Provide LGBTI health education

Health education is an important aspect of the right to health for LGBTI individuals. However, school curricula often fail to address LGBTI health education needs. In many countries, educational materials that address sexual orientation and gender identity issues, or even acknowledge the existence of LGBTI concerns, are banned from schools. In many countries around the world the hetero-norm is reinforced through withholding education about sexual and gender diversity,<sup>70</sup> and risking the health of young LGBTI people in the process.<sup>71</sup>

66 International Gay and Lesbian Human Rights Commission (IGLHRC), *Off the Map: How HIV/AIDS Programming is Failing Same-Sex Practicing People in Africa* (2007). <http://www.iglhrc.org/sites/default/files/6-1.pdf>.

67 International Gay and Lesbian Human Rights Commission (IGLHRC), “Moving the Mountain: Getting HIV Programmers and Policymakers to Pay Attention to the Needs of Men Who Have Sex with Men in Kenya,” Press Release (March 8, 2007); International Gay and Lesbian Human Rights Commission (IGLHRC), “IGLHRC’s New Study Reveals How Anti-Gay Discrimination Fuels HIV/AIDS Crisis in Africa,” Press Release (March 1, 2007). <http://www.iglhrc.org/content/africa-iglhrcs-new-study-reveals-how-anti-gay-discrimination-fuels-hiv-aids-crisis-africa>.

68 Morgan W, “Queering International Human Rights” in Stychin C and Herman D, eds., *Law and Sexuality: The Global Arena* (Minneapolis: University of Minnesota Press, 2001) at 208, 209.

69 For example, Nadine Gartner writes of how the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) “fails to adequately represent lesbians ... [t]he woman who emerges from CEDAW is heterosexual, married, with children, and primarily focused on her home” in Gartner N, “Articulating Lesbian Human Rights: The Creation of a Convention on the Elimination of All Forms of Discrimination Against Lesbians,” 14 *UCLA Women’s Law Journal* (2005) 61.

70 Armstrong KK, “The Silent Minority Within a Minority: Focusing on the Needs of Gay Youth in our Public Schools,” 24 *Golden Gate University Law Review* (1994) 67.

71 Pedrioli CA, “Lifting the Pall of Orthodoxy: The Need for Hearing a Multitude of Tongues in and Beyond the Sexual Education curricula at Public High Schools,” 13 *UCLA Women’s Law Journal* (2005) 209, at 211-2.

## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO LGBTI HEALTH?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments standards in so far as they relate to the health of the LGBTI community. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to LGBTI health. The tables are organized as follows:

Human right or fundamental freedom	
Examples of Human Rights Violations	
<b>Yogyakarta Principle</b> Provides the Yogyakarta principle and their origins.	
Human rights standards	<b>UN treaty body interpretation</b> This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.
Human rights standards	<b>Case law</b> This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.
<b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by: <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and LGBTI health.

## Abbreviations

In the tables, we use the following abbreviations to refer to the twelve treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment ( <b>CAT</b> )	Committee against Torture ( <b>CAT</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).



**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC	Yogyakarta Principles
Life	Art. 3	Art. 6(1)				Art. 6(1)	Principle 4
Torture or Cruel, Inhuman or Degrading Treatment*	Art. 5	Art. 7				Art. 37(a)	Principle 10
Bodily Integrity							
Non-Discrimination and Equality	Art. 1 Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5 All	Art. 2	Principle 2
Health	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 24	Principle 17
Privacy	Art. 12	Art. 17				Art. 16	Principle 6
Arbitrary Arrest and Detention	Art. 9	Art. 9				Art. 37(b)	Principle 7
Assembly and Association	Art. 20	Art. 21, Art. 22			Art. 5(d) (ix)	Art. 15	Principle 20
Expression and Information	Art. 19	Art. 19			Art. 5(d) (viii)	Art. 12, Art. 13, Art. 17	Principle 19
Marry and Form a Family	Art. 16	Art. 23		Art. 16	Art. 5(d) (iv)		Principle 24
Education	Art. 26		Art. 13	Art.10	Art. 5(e) (v)	Art. 28, Art. 29	Principle 16
Work	Art. 23		Art. 6, Art. 7	Art.11	Art.5(e) (i)		Principle 12
Social security	Art. 22		Art. 9	Art. 14(2)(c)	Art5(e) (iv)	Art. 26	Principle 13

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

**Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Life	Art. 4	Art. 2		Art. I	Art. 4
Torture or Cruel, Inhuman or Degrading Treatment	Art. 5	Art. 3			Art. 5(2)
Bodily Integrity					
Non-Discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Privacy		Art. 8		Art. V	Art. 11
Arbitrary Arrest and Detention	Art. 6	Art. 5		Art. XXV	Art. 7(3)
Assembly and Association	Art. 10, Art. 11	Art. 11		Art. XXI, Art. XXII	Art 15, Art. 16
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Marry and Form a Family		Art. 12		Art. VI	Art. 17
Education	Art.17			Art. XII	
Work	Art. 15		Art. 1	Art. XIV	
Social Security				Art. XVI	

**Table 1: LGBTI Health and the Right to Life**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>National laws which impose the death penalty for sexual activity between persons of the same sex.</li> <li>Police officers are not tried or prosecuted for the rape and murder of a homeless transgender person.</li> <li>LGBTI communities are denied access to services to prevent HIV.</li> <li>No laws are in place prohibiting hate crimes, including violence against LGBTI persons, which means police fail to investigate murders of LGBTI persons.</li> </ul>	
Yogyakarta Principle	
<p><b>Principle 4:</b> Everyone has the right to life. No one shall be arbitrarily deprived of life, including by reference to considerations of sexual orientation or gender identity. The death penalty shall not be imposed on any person on the basis of consensual sexual activity among persons who are over the age of consent or on the basis of sexual orientation or gender identity.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>Repeal crimes that have the purpose or effect of prohibiting consensual sexual activity among persons of the same sex who are over the age of consent and, until such provisions are repealed, never impose the death penalty on any person convicted under them;</li> <li>Remit sentences of death and release all those currently awaiting execution for crimes relating to consensual sexual activity among persons who are over the age of consent; and</li> <li>Cease any State-sponsored or State-condoned attacks on the lives of person based on sexual orientation or gender identity, and ensure that all such attacks, whether by government officials or by an individual or group, are vigorously investigated, and that, where appropriate evidence is found, those responsible are prosecuted, tried and duly punished.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 6(1)</b> Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.</p> <p><b>ICCPR 6(2)</b> In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgment rendered by a competent court.</p>	<p><b>HRC General Comment 6 and 31:</b> States have an obligation to take appropriate measures or to exercise due diligence to prevent, punish, investigate or redress the harm caused by deprivations of life by private entities. They must also prevent deprivation of life by their own agents. This includes where victims are deprived of life on the basis of their sexual orientation or gender identity. HRC General Comment No. 6 (1982) at para. 3; and HRC General Comment 31, CCPR/C/21/Rev.1/Add. 13 (2004) at para. 8.</p> <p><b>HRC:</b> recommending that <b>El Salvador</b> “should provide effective protection against violence and discrimination based on sexual orientation.” CCPR/CO/78/SLV (2003) at para. 16.</p> <p><b>HRC:</b> recommending that the <b>United States</b> “should ensure that its hate crime legislation, both at the federal and state levels, address sexual orientation-related violence.” CCPR/C/USA/CO/3 (2006) at para. 25.</p> <p><b>HRC:</b> recommending that <b>Mongolia</b> “should ensure that LGBT persons have access to justice, and that all allegations of attacks and threats against individuals targeted because of their sexual orientation or gender identity are thoroughly investigated.” CCPR/C/MNG/CO/5 (2011) at para. 9.</p> <p><b>HRC:</b> recommending that <b>Jamaica</b> should ensure that individuals, who incite violence against LGBTI persons, are investigated, prosecuted and properly sanctioned. CCPR/C/JAM/CO/3 (2011) at para 8.</p> <p><b>HRC:</b> noting to <b>Colombia</b> that the Committee deplores systematic operations targeted at executing homosexuals. CCPR/C/79/Add.76 (1997) at para. 16.</p>

**Table I (cont.)**

Human Rights Standards	Treaty Body Interpretation
<b>CRC 6 (1)</b> States Parties recognize that every child has the inherent right to life.	<b>CRC General Comment No. 3:</b> The obligation to realize the right to life, survival and development also highlights the need to give careful attention to sexuality as well as to the behaviors and lifestyles of children, even if they do not conform with what society determines to be acceptable under prevailing cultural norms. CRC/GC/2003/3 (2003) at para. 11.

Human Rights Standards	Case Law
<b>ECHR 2(1)</b> Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.	
<b>ACHR 4(1)</b> Every person has the right to have his life respected. This right shall be protected by law and, in general, from the moment of conception. No one shall be arbitrarily deprived of his life.	

**Other Interpretations**

**SR on Extrajudicial, Summary or Arbitrary Executions:** Capital punishment should not be applied to “moral” offences. States must prevent and investigate the killing of sexual minorities by non-state actors.

**SR on Extrajudicial, Summary or Arbitrary Executions:** “Acts of murder and death threats should be promptly and thoroughly investigated regardless of the sexual orientation of the victims. Measures by the State to protect the security and right to life of sexual minorities should include policies and programmes geared towards overcoming hatred and prejudice against homosexuals and sensitizing public officials and the general public to crimes and acts of violence directed against members of sexual minorities ... Matters of sexual orientation should under no circumstances be punishable by death.” Report of the Special Rapporteur on Extrajudicial, Summary or Arbitrary Executions, E/CN.4/2000/3 (2002) at para. 116.

**SR on Health:** “Sanctioned punishments by States reinforce existing prejudices and legitimizes community violence and police brutality directed at affected individuals ... The Special Rapporteur believes that the imposition of the death penalty for consensual same sex conduct is not only unconscionable, but further represents arbitrary deprivation of life, constituting an infringement of the right to life recognized in article 6 of the International Covenant on Civil and Political Rights.” Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/14/20 (2010) at para. 20.

## Table 2: LGBTI Health and Freedom from Torture or Cruel, Inhuman, or Degrading Treatment

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• A psychiatrist provides “treatment” to an LGBTI person with electric shock or hormone therapy without consent.</li> <li>• A gay man in prison is denied a bed and repeatedly assaulted and raped by cell mates, with the complicity or inaction of prison guards and correctional officials.</li> <li>• Police torture a lesbian couple, because of their sexual orientation, and there is a failure to investigate the actions of the police officers.</li> </ul>	
Yogyakarta Principle	
<p><b>Principle 10:</b> Everyone has the right to be free from torture and from cruel, inhuman or degrading treatment or punishment, including for reasons relating to sexual orientation or gender identity.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>• Take all necessary legislative, administrative and other measure to prevent and provide protection from torture and cruel, inhuman or degrading treatment or punishment, perpetrated for reasons relating to the sexual orientation or gender identity of the victim, as well as the incitement of such acts;</li> <li>• Take all reasonable steps to identify victims of torture and cruel, inhuman or degrading treatment or punishment, perpetrated for reasons relating to sexual orientation or gender identity, and offer appropriate remedies including redress and reparation and, where appropriate, medical and psychological support;</li> <li>• Undertake programmes of training and awareness-raising for police, prison personnel and all other officials in the public and private sector who are in a position to perpetrate or to prevent such acts.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 7</b> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.</p>	<p><b>HRC General Comment No. 31:</b> The failure to investigate and bring to justice perpetrators of torture or ill treatment in and of itself can give rise to a separate breach of international law. CCPR/C/21/Rev.1/Add.13 (2004) at para 18.</p> <p><b>HRC:</b> recommending that <b>Ecuador</b> “should take preventive and protective measures to ensure that persons of a different sexual orientation are not detained in private clinics or rehabilitation centres in order to be subjected to ‘sexual reorientation’ treatments” and “investigate the alleged detentions and torture and adopt the necessary remedial measures in accordance with the Constitution.” CCPR/C/ECU/CO/5 (2009) at para. 12.</p>

**Table 2 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CAT 2(1)</b> Each State Party shall take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under its jurisdiction.</p>	<p><b>CAT General Comment 2:</b> “The protection of certain minority or marginalized individuals or populations especially at risk of torture is a part of the obligation to prevent torture or ill-treatment. States parties must ensure that ... their laws are in practice applied to all persons, regardless of ... gender, sexual orientation, transgender identity... States parties should ensure the protection of members of groups especially at risk of being tortured, by fully prosecuting and punishing all acts of violence and abuse against these individuals and ensuring implementation of other positive measures of prevention and protection, including but not limited to those outlined above.” CAT/C/GC/2 (2008) at para. 21.</p> <p><b>CAT:</b> expressing concern that in the <b>United States</b> “that there are numerous reports of sexual violence perpetrated by detainees on one another, and that persons of differing sexual orientation are particularly vulnerable” and recommending that it “design and implement appropriate measures to prevent all sexual violence in all their detention centres.” CAT/C/USA/Co/2 (2006) at paras. 32</p> <p><b>CAT:</b> recommending that the <b>United States</b> “ensure that reports of brutality and ill-treatment of members of vulnerable groups by its law-enforcement personnel are independently, promptly and thoroughly investigated and that perpetrators are prosecuted and appropriately punished.” CAT/C/USA/Co/2 (2006) at paras. 37.</p> <p><b>CAT:</b> recommending to <b>Egypt</b> that it “remove all ambiguity in legislation which might underpin the persecution of individuals because of their sexual orientation. Steps should also be taken to prevent all degrading treatment during of body searches.” Here the Committee is referring to use of anal exams to ‘prove’ homosexuality as degrading treatment. CAT/C/CR/29/4 (2002) at para. 6(k).</p> <p><b>CAT:</b> expressing concern to <b>Argentina</b> at “[a]llegations of torture and ill-treatment of certain other vulnerable groups, such as members of the indigenous communities, sexual minorities and women.” CAT/C/CR/33/1, para 6(g).</p> <p><b>CAT:</b> recommending that <b>Mongolia</b> “establish a comprehensive legal framework to combat discrimination, including hate crimes and speech. The State party should take measures to bring perpetrators of such crimes to justice. The State party should ensure the protection of vulnerable groups such as sexual minorities, persons living with HIV/AIDS, and some foreigners. The State party should establish effective policing, enforcement and complaints mechanisms with a view to ensuring prompt, thorough and impartial investigations into allegations of attacks against persons on the basis of their sexual orientation or gender identity in line with the Yogyakarta Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity.” CAT/C/MNG/CO/1, para. 25.</p> <p><b>CAT:</b> recommending that <b>Kuwait</b> “investigate crimes related to discrimination directed towards all vulnerable groups and pursue ways in which hate crimes can be prevented and punished. The Committee is concerned at reports that vulnerable groups such as lesbian, gay, bisexual and transgender (LGBT) persons are subjected to discrimination and ill-treatment, including sexual violence, both in public and domestic settings. (arts. 2 and 16).” CAT/C/KWT/CO/2, para. 25.</p>

Human Rights Standards	Case Law
<p><b>ECHR 3</b> No one shall be subjected to torture or to inhuman or degrading treatment or punishment.</p>	<p><b>ECtHR:</b> finding discharge from the armed services on account of applicant’s sexuality “undoubtedly distressing and humiliating [.]” but <b>not</b> a violation of Art. 3. <i>Smith and Grady v. The United Kingdom</i>, 33985/96 (Sep. 27,1999), emphasis added.</p>

## Table 2 (cont.)

### Other Interpretations

**SR Torture:** Has expressed concern at torture and cruel, inhuman or degrading treatment directed at persons because of their sexual orientation or gender identity or expression, noting that torture and cruel, inhuman or degrading treatment protections apply in criminal detention as well as to health and immigration facilities.

**WG on Arbitrary Detention:** "... Forced anal examinations contravene the prohibition of torture and other cruel, inhuman and degrading treatment, whether if, like in the present cases, they are employed with a purpose to punish, to coerce a confession, or to further discrimination." WG on Arbitrary Detention, A/HRC/16/47/Add.1, Opinion No. 25/2009 on Egypt at paras. 23, 28-29.

**Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.** <http://www.ohchr.org/Documents/Publications/training8Rev1en.pdf>.

**Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment,** G.A. Res. 37/194, UN Doc. No. A/RES/37/194 (Dec. 18, 1982). <http://www2.ohchr.org/english/law/medicalethics.htm>.

**Code of Conduct for Law Enforcement Officials,** G.A. Res. 34/169, UN Doc. A/RES/34/169 (Dec. 17, 1979). <http://www2.ohchr.org/english/codeofconduct.pdf>.

**Declaration on the Protection of All Persons from Being Subjected to Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment** ("Declaration Against Torture"), adopted by consensus by the UN Assembly (UN G.A. Res. 3452 [XXX] (Dec. 9, 1975)).

**Vienna Declaration and Programme of Action,** Para. 56: "[U]nder human rights law and international humanitarian law, freedom from torture is a right which must be protected under all circumstances, including in times of internal or international disturbance or armed conflicts."

**European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment,** *opened for signature* Nov. 26, 1987, E.T.S. No. 126 (entered into force Jan. 2, 1989). Available at <http://www.cpt.coe.int/en/documents/ecpt.htm>

**Inter-American Convention to Prevent and Punish Torture** (1985)

**Inter-American Commission on Human Rights,** press release (August 15, 2013). [http://oas.org/en/iachr/media\\_center/PReleases/2013/060.asp](http://oas.org/en/iachr/media_center/PReleases/2013/060.asp).

The Inter-American Commission recalls that it is the States' obligation to investigate killings and other acts of violence against LGBTI persons and sanction those responsible. The IACHR urges the States to open lines of investigation that take into account whether these murders and acts of violence were committed because of the gender identity, gender expression and/or sexual orientation of the victims. In general terms, the Commission notes that there are problems in the investigation of these crimes. In this regard, the Inter-American Commission reiterates that the ineffectiveness of the state's response fosters high rates of impunity, which in turn lead to the chronic repetition of such crimes, leaving the victims and their families defenseless.



## Table 3: LGBTI Health and the Right to Bodily Integrity

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A transsexual or transgender person is raped or assaulted by police.</li> <li>• A lesbian is raped by family friends to “make her straight”.</li> <li>• The police fail to investigate beatings and sexual assaults of men having sex with men.</li> <li>• Schools fail to protect students from attacks for sexual or gender non-conformity.</li> <li>• A transgender person is sterilized against his or her will.</li> <li>• Forced anal exams of men who have sex with men (MSM) as part of arrest procedure.</li> <li>• Transgendered person is denied services or insurance coverage for services such as hormone replacement therapy and gender reassignment surgery.</li> </ul>
Note On Bodily Integrity in International and National Treaties
<p>The right to bodily integrity is not explicitly set out in the Yogyakarta Principles, but is implicitly included in the right to life, right to security of the person, freedom from torture and cruel, degrading treatment and right to highest attainable standard of health, which are included in the Yogyakarta Principles.</p> <p>The right to bodily integrity is not specifically recognized under the ICCPR or ICESCR, but has been interpreted to be part of the right to security of the person, to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health. Similarly, the right to bodily integrity is not specifically recognized in CEDAW, although CEDAW has been widely interpreted to include the right to protection from violence against women.</p>

### Other Interpretations

**WG Enforced or Involuntary Disappearances:** An aspect of disappearances that has been underreported in the past and continues at the present time relates to the way in which acts of disappearance are perpetrated in conjunction with other gross violations, with targets drawn from among the most vulnerable groups in society...Common examples include: disappearances, combined with ‘social cleansing,’ the urban poor, the unemployed, and the so-called ‘undesirables,’ including prostitutes, petty thieves, vagabonds, gamblers and homosexuals as the victims.

**Inter-American Commission on Human Rights** (August 15, 2013), [http://oas.org/en/iachr/media\\_center/PReleases/2013/060.asp](http://oas.org/en/iachr/media_center/PReleases/2013/060.asp):

The Inter-American Commission urges States to take all necessary measures to apply due diligence in preventing, investigating and sanctioning violence against LGBTI persons, regardless of whether it occurs in the family, the community, or the public sphere, including education and health facilities. This includes the adoption of policies and public campaigns to promote awareness and respect for the human rights of LGBTI persons, in all sectors, including the educational and family settings, as a means to combat the prejudices that underlie violence related to sexual orientation and gender identity and expression. Finally, the Commission urges States to take action to prevent and respond to these human rights violations and to ensure that LGBTI persons can effectively enjoy their right to a life free from discrimination and violence.

**Inter-American Commission on Human Rights** (October 29, 2012), [http://oas.org/en/iachr/media\\_center/PReleases/2012/129.asp](http://oas.org/en/iachr/media_center/PReleases/2012/129.asp):

The Commission continues to receive information on killings, torture, arbitrary arrests, and other forms of violence and exclusion against lesbians, gays, and trans, bisexual, and intersex persons. In addition, the Commission notes that problems exist in the investigation of those crimes, which involve, in part, failures to open lines of investigation into whether the crime was committed by reason of the victim’s gender identity or sexual orientation. The ineffectiveness of the state response fosters high rates of impunity, which in turn lead to the chronic repetition of such crimes, leaving the victims and their families defenseless.

The IACHR urges the States to take action to prevent and respond to these human rights abuses and to ensure that LGBTI people can effectively enjoy their right to a life free from discrimination and violence, including the adoption of policies and public campaigns and the amendments necessary to bring laws into line with the inter-American instruments on human rights.

**European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment** (2001), No. 126: Stated that Every competent patient...should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances.

**Table 4: LGBTI Health and the Right to Non-discrimination**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A person is denied a job, housing, health care, education, or access to goods and services because of sexual orientation, gender identity or gender expression.</li> <li>• A TV program is prohibited by authorities because it features a same-sex kiss while allowing different-sex kisses to be aired regularly.</li> <li>• An organization for boys (e.g, Boy Scouts) denies membership to LGBTI people.</li> </ul>
Yogyakarta Principle
<p><b>Principle 2:</b> Everyone is entitled to enjoy all human rights without discrimination on the basis of sexual orientation or gender identity. Everyone is entitled to equality before the law and the equal protection of the law without any such discrimination whether or not the enjoyment of another human right is also affected. The law shall prohibit any such discrimination and guarantee to all persons equal and effective protection against any such discrimination.</p> <p>Discrimination on the basis of sexual orientation or gender identity includes any distinction, exclusion, restriction or preference based on sexual orientation or gender identity which has the purpose or effect of nullifying or impairing equality before the law or the equal protection of the law, or the recognition, enjoyment or exercise, on an equal basis, of all human rights and fundamental freedoms. Discrimination based on sexual orientation or gender identity may be, and commonly is, compounded by discrimination on other grounds including gender, race, age, religion, disability, health and economic status.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>• Embody the principles of equality and non-discrimination on the basis of sexual orientation and gender identity in national constitutions or other appropriate legislation;</li> <li>• Repeal legal provisions that have the effect of prohibiting consensual sexual activity between people of the same sex who are over the age of consent, and to ensure that an equal age of consent applies to all, regardless of their sexual orientation or gender identity;</li> <li>• Adopt legislation and other measures to prohibit and eliminate discrimination on the basis of sexual orientation and gender identity;</li> <li>• Take appropriate measures to secure adequate advancement of persons of diverse sexual orientation and gender identities as may be necessary to ensure such groups have equal enjoyment of human rights;</li> <li>• When responding to discrimination based on sexual orientation and gender identity, take into account the manner in which such discrimination intersects with other forms of discrimination; and</li> <li>• Take all appropriate action to achieve elimination of prejudicial or discriminatory attitudes or behaviours related to the idea of inferiority or superiority of any sexual orientation or gender identity.</li> </ul>

**Table 4 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 2(1)</b> Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.</p>	<p><b>HRC:</b> expressing concern to <b>Chile</b> “about the discrimination to which some people are subject because of their sexual orientation, for instance, before the courts and in access to health care” and recommending that it “guarantee equal rights to all individuals, as established in the Covenant, regardless of their sexual orientation, including equality before the law and in access to health care. CCPR/C/CHL/CO/5 (2007) at para. 16.</p> <p><b>HRC:</b> expressing concern to <b>Ireland</b> that it “has not recognized a change of gender by transgender persons by permitting birth certificates to be issued for these persons” and recommending that Ireland “should recognize the right of transgender persons to a change of gender by permitting the issuance of new birth certificates.” Birth certificates provide legal recognition to changes of an individual’s gender identity. CCPR/C/IRL/CO/3 (2008) at para. 8.</p> <p><b>HRC:</b> recommending that <b>Iran</b> “should also take all necessary legislative, administrative and other measures to eliminate and prohibit discrimination on the basis of sexual orientation, including with respect to access to employment, housing, education and health care, and to ensure that individuals of different sexual orientation or gender identity are protected from violence and social exclusion within the community.” CCPR/C/IRN/CO/3 (2011) at para. 10.</p> <p><b>HRC [Jurisprudence]:</b> Has recognized the right to non-discrimination on the basis of sexual orientation in relation to privacy (<i>Toonen v. Australia</i>, HRC Communication No. 488/1992 (CCPR/C/50/D/488/1992)), and access to benefits (<i>Young v. Australia</i>, HRC Communication No. 941/2000 (CCPR/C/78/O/941/2000)), but not access to marriage (<i>Joslin v. New Zealand</i>, HRC Communication No. 902/1999 (CCPR/C/75/D/902/1999)).</p> <p><b>HRC:</b> expressing concern to <b>Poland</b> that “discriminatory acts and attitudes against persons on the ground of sexual orientation are not adequately investigated and punished” and recommending that Poland “should provide appropriate training to law enforcement and judicial officials in order to sensitize them to the rights of sexual minorities.” CCPR/CO/82/POL (2004) at para. 18.</p> <p><b>HRC:</b> recommended that the <b>United States</b> “acknowledge legal obligation under articles 2 and 26 to ensure to everyone rights recognized by ICCPR, as well as equality before law and equal protection of law, without discrimination on basis of sexual orientation [and] ensure that its hate crime legislation, both at federal and state levels, address sexual orientation-related violence and that federal and state employment legislation outlaw discrimination on basis of sexual orientation.” CCPR/C/USA/CO/3 (HRC, 2006)</p> <p><b>HRC:</b> recommended that <b>Mongolia</b> “should ensure that LGBT persons have access to justice, and that all allegations of attacks and threats against individuals targeted because of their sexual orientation or gender identity are thoroughly investigated.” CCPR/C/MNG/CO/5 (HRC, 2011)</p>

**Table 4 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 2(2)</b> The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status.</p>	<p><b>CESCR General Comment No. 20:</b> The prohibited grounds of discrimination in ICESCR Article 2(2) includes ‘other status’. In General Comment 20, CESCR establishes that ‘other status’ includes sexual orientation and gender identity. Therefore, sexual orientation and gender identity are prohibited grounds of discrimination under ICESCR. E/C.12/GC/20 (2009) at para 32.</p> <p><b>CESCR:</b> urging <b>Germany</b> to “step up measures, legislative or otherwise, on the identity and the health of transsexual and inter-sex persons with a view to ensuring that they are no longer discriminated against and that their personal integrity and sexual and reproductive health rights are respected. The Committee calls on the State party to fully consult transsexual and inter-sexed persons for this purpose.” E/C.12/DEU/CO/5 (2011) at para. 26.</p> <p><b>CESCR:</b> recommending to <b>Poland</b> that it should adopt legislative and other measures to eliminate and prohibit discrimination against LGBTI persons in the enjoyment of their economic, social and cultural rights. E/C.12/POL/CO/5 (2009) at para. 12.</p>
<p><b>CRC 2(1)</b> States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child’s or his or her parent’s or legal guardian’s race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.</p> <p><b>CRC 2(2)</b> States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child’s parents, legal guardians, or family members.</p>	<p><b>CRC General Comment No. 13:</b> explaining that “States parties must address discrimination against vulnerable or marginalized groups of children ... and make proactive efforts to ensure that such children are assured their right to protection on an equal basis with all other children.” Explaining that vulnerable children includes children “who are lesbian, gay, transgender or transsexual.” CRC/C/GC/13 (2011) at paras. 60 and 72(g).</p> <p><b>CRC General Comment No. 4:</b> “States parties have the obligation to ensure that all human beings below 18 enjoy all the rights set forth in the Convention without discrimination (art. 2), including with regard to “race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status”. These grounds also cover adolescents’ sexual orientation and health status (including HIV/AIDS and mental health). Adolescents who are subject to discrimination are more vulnerable to abuse, other types of violence and exploitation, and their health and development are put at greater risk. They are therefore entitled to special attention and protection from all segments of society.” CRC/GC/2003/4 (2003) at para. 6.</p> <p><b>CRC Committee:</b> recommending that the <b>United Kingdom of Great Britain and Northern Island</b> should strengthen its “awareness-raising and other preventative activities against discrimination and, if necessary, taking affirmative actions” for LGBTI children. CRC/C/GBR/CP/4 at paras. 24-25.</p> <p><b>CCRC Committee:</b> expressing concern to <b>Chile</b> “that homosexual relations, including those of persons under 18 years old, continue to be criminalized, indicating discrimination on the basis of sexual orientation.” CRC/C/CHL/CO/3</p>
<p><b>CAT 1(1)</b> For the purposes of this Convention, the term “torture” means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person...for any reason based on discrimination of any kind...</p>	<p><b>CAT General Comment No. 2:</b> States must ensure that their laws are in practice applied to all persons, regardless of their sexual orientation or transgender identity. CAT/C/GC/2 (2007) at para. 21.</p>

**Table 4 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CEDAW 2</b> States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women...</p>	<p><b>CEDAW General Recommendation No. 28:</b> “The discrimination of women based on sex and gender is inextricably linked with other factors that affect women, such as...sexual orientation and gender identity...States parties must legally recognise such intersecting forms of discrimination and their compounded negative impact on the women concerned and prohibit them.” CEDAW/C/GC/28 (2010), at para. 18.</p> <p><b>CEDAW:</b> recommending that <b>Uganda</b> “decriminalize homosexual behaviour and to provide effective protection from violence and discrimination against women based on their sexual orientation and gender identity, in particular through the enactment of comprehensive anti-discrimination legislation that would include the prohibition of multiple forms of discrimination against women on all grounds, including on the grounds of sexual orientation and gender identity.” CEDAW/C/UGA/CO/7</p>

### Other Interpretations

**Inter-American Convention Against All Forms of Discrimination and Intolerance**, AG/RES. 2804 (XLIII-O/13), (June 6, 2013).

**Article 1(1)** Discrimination shall mean any distinction, exclusion, restriction, or preference, in any area of public or private life, the purpose or effect of which is to nullify or curtail the equal recognition, enjoyment, or exercise of one or more human rights and fundamental freedoms enshrined in the international instruments applicable to the States Parties. Discrimination may be based on nationality; age; sex; **sexual orientation; gender identity and expression**; language; religion; cultural identity; political opinions or opinions of any kind; social origin; socioeconomic status; educational level; migrant, refugee, repatriate, stateless or internally displaced status; disability; genetic trait; mental or physical health condition, including infectious-contagious condition and debilitating psychological condition; or any other condition.

**Charter of Fundamental Rights of the European Union (“European Charter”) 21(1):** Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age, or sexual orientation shall be prohibited.

**Lisbon Treaty:** In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

**Inter-American Commission on Human Rights**, press release (August 15, 2013). [http://oas.org/en/iachr/media\\_center/PReleases/2013/060.asp](http://oas.org/en/iachr/media_center/PReleases/2013/060.asp):

The Inter-American Commission urges States to take all necessary measures to apply due diligence in preventing, investigating and sanctioning violence against LGBTI persons, regardless of whether it occurs in the family, the community, or the public sphere, including education and health facilities. This includes the adoption of policies and public campaigns to promote awareness and respect for the human rights of LGBTI persons, in all sectors, including the educational and family settings, as a means to combat the prejudices that underlie violence related to sexual orientation and gender identity and expression. Finally, the Commission urges States to take action to prevent and respond to these human rights violations and to ensure that LGBTI persons can effectively enjoy their right to a life free from discrimination and violence.

## Table 5: LGBTI Health and the Right to the Highest Attainable Standard of Health

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A national health system fails to provide anti-retroviral treatment to LGBTI people while making it accessible to others.</li> <li>• Perceived LGBTI persons are treated with stigma and judgmental attitudes in the health system and therefore are not providing equal levels of health.</li> <li>• Because of stigma in the health system LGBTI individuals do not feel comfortable accessing health care facilities.</li> <li>• Men who have sex with men (MSM) and other marginalized populations are regularly left out of national health and budget plans, thereby ensuring that services are not funded and available. Because of stigma in the health system, LGBTI individuals do not feel comfortable.</li> </ul>
Yogyakarta Principle
<p><b>Principle 17:</b> Everyone has the right to the highest attainable standard of physical and mental health, without discrimination on the basis of sexual orientation or gender identity. Sexual and reproductive health is a fundamental aspect of this right.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>• Take all legislative, administrative and other measures to ensure enjoyment of the right and to ensure all persons have access to healthcare facilities, goods and services, and to their own medical records;</li> <li>• Ensure healthcare facilities, goods and services are designed to improve the health status of, and respond to the needs of all persons without discrimination on the basis of, and taking into account, sexual orientation and gender identity;</li> <li>• Develop and implement programmes to address discrimination, prejudicial and social factors which undermine the health of persons because of their sexual orientation and gender identity;</li> <li>• Ensure all persons are informed and empowered to make their own decisions regarding medical treatment and care, on the basis of genuinely informed consent;</li> <li>• Ensure that all sexual and reproductive health, education, prevention, care and treatment programmes and services respect the diversity of sexual orientations and gender identities, and are equally available to all without discrimination;</li> <li>• Facilitate access by those seeking body modifications related to gender reassignment to competent, non-discriminatory treatment, care and support;</li> <li>• Ensure that all health service providers treat clients and their partners without discrimination on the basis of sexual orientation or gender identity, including with regard to recognition as next of kin; and</li> <li>• Adopt policies, and programmes of education and training, necessary to enable persons working in the healthcare sector to deliver the highest attainable standard of healthcare to all persons, with full respect for each person's sexual orientation and gender identity.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p> <p><b>ICESCR 12(2)</b> The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases.</p>	<p><b>CESCR General Comment 14:</b> The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable standard of health. E/C.12/2000/4 (2000) at para. 8.</p> <p><b>CESCR General Comment 14:</b> It is prohibited to discriminate against access to health care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of sexual orientation. E/C.12/2000/4 (2000) at para. 18.</p> <p><b>CESCR:</b> States have an immediate obligation to ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups. E/C.12/2000/4 (2000) at para. 43(a).</p>

### Other Interpretations

**SR Health:** “Criminal laws concerning consensual same-sex conduct, sexual orientation and gender identity often infringe on various human rights, including the right to health. These laws are generally inherently discriminatory and, as such, breach the requirements of a right-to-health approach, which requires equality in access for all people. The health related impact of discrimination based on sexual conduct and orientation is far-reaching, and prevents affected individuals from gaining access to other economic, social and cultural rights. In turn, the infringement of other human rights impacts on the realization of the right to health, such as by impeding access to employment or housing.” Report of the SR on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/14/20 (2010) at para. 6.

**The Declaration on the Promotion of Patients’ Rights in Europe:** Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider.

**WHO 1978 Declaration of Alma-Ata:** The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal, which requires the action of many other social and economic sectors in addition to the health sector to be fully realized.

**World Health Organization Constitution, Preamble:** The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

**Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (1988) (“Protocol of San Salvador”),** Art. 10(1): Everyone shall have the right to health, understood to mean the enjoyment of the highest level of physical, mental and social well-being.

**European Convention on Social and Medical Assistance (1953),** Art. 1: Each of the Contracted Parties undertake to ensure that nationals of the other Contracting Parties who are lawfully present in any part of its territory to which the Convention applies, and who are without sufficient resources, shall be entitled equally with its own nationals and on the same conditions to social and medical assistance . . . provided by the legislation in force from time to time in that part of its territory.

**Charter of Fundamental Rights of the European Union,** Art. 35: Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.



## Table 6: LGBTI Health and the Right to Privacy

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• A penal code that punishes non-reproductive sex, such as any form of anal or oral sex, or same-sex sexual behaviour.</li> <li>• Police officials keep lists of “suspected homosexuals” with photographs and fingerprints.</li> <li>• A newspaper publishes an article condemning the sexual orientation of a teacher or journalist.</li> <li>• Police or public health officials release the photos of suspected gay men to the media.</li> </ul>	
Yogyakarta Principle	
<p><b>Principle 6:</b> Everyone, regardless of sexual orientation or gender identity, is entitled to the enjoyment of privacy without arbitrary or unlawful interference, including with regard to their family, home or correspondence as well as to protection from unlawful attacks on their honour and reputation. The right to privacy ordinarily includes the choice to disclose or not to disclose information relating to one’s sexual orientation or gender identity, as well as decisions and choices regarding both one’s own body and consensual sexual and other relations with others.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>• Take all necessary legislative, administrative, and other measures to ensure the right of each person, regardless of sexual orientation or gender identity, to enjoy the private sphere, intimate decisions, and human relations including consensual sexual activity among persons who are over the age of consent, without arbitrary interference;</li> <li>• Repeal all laws that criminalise consensual sexual activity among person of the same sex who are over the age of consent, and ensure that an equal age of consent applies to both same-sex and different-sex sexual activity;</li> <li>• Ensure the criminal and other legal provisions of general application are not applied to <i>de facto</i> criminalised consensual sexual activity among persons of the same sex who are over the age of consent;</li> <li>• Repeal any law that prohibits or criminalises the expression of gender identity, including through dress, speech or mannerisms, or that denies to individuals the opportunity to change their bodies as a means of expressing their gender identity;</li> <li>• Release all those held on remand or on the basis of criminal conviction, if their detention is related to consensual sexual activity among persons who are over the age of consent, or is related to gender identity; and</li> <li>• Ensure the right of all persons ordinarily to choose when, to whom and how to disclose information pertaining to their sexual orientation or gender identity, and protect all persons from arbitrary or unwanted disclosure, or threat of disclosure of such information by others.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 17(1)</b> No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.</p> <p><b>ICCPR 17(2)</b> Everyone has the right to the protection of the law against such interference or attacks.</p>	<p><b>HRC [Jurisprudence]:</b> The penalization of same-sex behaviour is a violation of privacy and non-discrimination under ICCPR articles 2 and 17. <i>Toonen v. Australia</i>, HRC Communication No. 488/1992 (CCPR/C/50/D/488/1992).</p> <p><b>HRC:</b> recommending to <b>Togo</b> that it “should decriminalize sexual relations between consenting adults of the same sex” because such “criminalization violates the rights to privacy and to protection against discrimination set out in the Covenant.” CCPR/C/TGO/CO/4 (2011) para 14.</p> <p><b>HRC:</b> recommending that “the State party should decriminalize sexual relations between consenting adults of the same sex, and repeal the offense of imitating the opposite sex, in order to bring its legislation in line with the covenant.” <b>Kuwait</b> CCPR/C/KWT/CO/2 (HRC, 2011); <b>Togo</b> CCPR/C/TGO/CO/4 (HRC, 2011); <b>Barbados</b> CCPR/C/BRB/CO/3 (HRC, 2007); <b>Jamaica</b> CCPR/C/JAM/CO/3 (HRC, 2011); <b>Cameroon</b> CCPR/C/CMR/CO/4 (HRC, 2010); <b>Uzbekistan</b> (CCPR/C/UZB/CO/3); <b>Grenada</b> (CCPR/C/GRD/CO/1).</p> <p><b>HRC:</b> Explaining to <b>Togo</b> that “As pointed out by the Committee and other international human rights bodies, such criminalization violates the rights to privacy and to protection against discrimination set out in the Covenant.” CCPR/C/TGO/CO/4 (2011) para 14.</p>

**Table 6 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<b>CRC 16 (1)</b> No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence, nor to unlawful attacks on his or her honour and reputation.	<p><b>CRC General Comment 4:</b> “In order to promote the health and development of adolescents, States parties are encouraged to strictly respect adolescent rights to privacy and confidentiality, including with respect to advice and counselling on health matters (article 16). Health-care providers have an obligation to keep confidential medical information concerning adolescents, bearing in mind the basic principles of the CRC. Such information may only be disclosed with the consent of the adolescent, or in the same situations applying to the violation of an adult’s confidentiality. Adolescents deemed mature enough to receive counselling without the presence of a parent or other person are entitled to privacy and may request confidential services, including treatment.” CRC/GC/2003/4 (2003) at para. 11.</p> <p><b>CRC General Comment 4:</b> “The realization of the right to health of adolescents is dependent on the development of youth-sensitive health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services.” CRC/GC/2003/4 (2003) at para. 40.</p>

Human Rights Standards	Case Law
<p><b>ECHR 8(1)</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><b>ECHR 8(2).</b> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p><b>ECTHR:</b> the Court held that the law in Northern Ireland creating criminal liability for homosexual conduct amounts to an unjustified interference with Dudgeon’s right to respect for his private life. <i>Case of Dudgeon v. The United Kingdom</i>, 7525/76 (Oct. 22, 1981).</p> <p><b>ECTHR:</b> the Court affirmed that the penalization of same sex behaviour violates the right to privacy (Dudgeon v. UK and later cases), and protected the right to transition from one gender to another, although not to remain between genders. <i>Case of Christine Goodwin v. The United Kingdom</i>, 28957/95 (July 11, 2002).</p> <p><b>ECTHR:</b> the defendants were prosecuted and convicted for assault and wounding in the course of consensual sado-masochistic activities between breaches. The applicants argued that this violated their right to privacy under Article 8. The Court held that “the national authorities were entitled to consider that the prosecution and conviction of the applicants were necessary in a democratic society for the protection of health within the meaning of Article 8 para. 2.” <i>Laskey, Jaggard and Brown v. The United Kingdom</i>, 21627/93 (Feb. 19, 1997).</p> <p><b>ECTHR:</b> the applicant was born and registered with the civil status register as a male. The applicant now lives as a female and was denied her application to correct the indication of her sex in the civil status register and on her official identity documents. The Court held that the State violated Article 8, because it did not strike a fair balance between the general interest and the interests of the individual. <i>Case of B v. France</i>, 13343/87 (Mar. 25, 1992).</p> <p><b>ECTHR:</b> the Court held that the State violated Article 8 because of its investigation into the applicants’ homosexuality and their subsequent discharge from the Royal Air Force. <i>Case of Smith and Grady v. The United Kingdom</i>, 33985/96 (Sep. 27, 1999).</p>

### Other Interpretations

**Declaration on the Promotion of Patients’ Rights in Europe** Art. 4.1: All information about a patient’s health status ... must be kept confidential, even after death. Art. 4.8: Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy.

**European Convention on Human Rights and Biomedicine** Art 10(1): “Everyone has the right to respect for private life in relation to information about his or her health.”

- Explanatory Report, para. 63: “The first paragraph establishes the right to privacy of information in the health field, thereby reaffirming the principle introduced in Article 8 of the European Convention on Human Rights and reiterated in the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data. It should be pointed out that, under Article 6 of the latter Convention, personal data concerning health constitute a special category of data and are as such subject to special rules.”
- Explanatory Report, para. 64: “However, certain restrictions to the respect of privacy are possible for one of the reasons and under the conditions provided for in under Article 26.1. For example, a judicial authority may order that a test be carried out in order to identify the author of a crime (exception based on the prevention of a crime) or to determine the filiation link (exception based on the protection of the rights of others).”

## Table 7: LGBTI Health and Freedom from Arbitrary Arrest and Detention

### Examples of Human Rights Violations

- A gay man is arrested without charge by undercover police officers.
- A lesbian adolescent is detained without charge after her parents discover her sexual orientation and call the police.
- A transgender is detained at a border for “suspicious behavior.”
- A transgender person suffers from illegal profiling.

### Yogyakarta Principle

**Principle 7:** No one shall be subjected to arbitrary arrest or detention. Arrest or detention on the basis of sexual orientation or gender identity, whether pursuant to a court order or otherwise, is arbitrary. All persons under arrest, regardless of their sexual orientation or gender identity, are entitled, on the basis of equality, to be informed of the reasons for arrest and the nature of any charges against them, to be brought promptly before a judicial officer and to bring court proceedings to determine the lawfulness of detention, whether or not charged with any offence.

States shall:

- Take all necessary legislative, administrative and other measures to ensure that sexual orientation or gender identity may under no circumstances be the basis for arrest or detention, including the elimination of vaguely worded criminal law provisions that invite discriminatory application or otherwise provide scope for arrests based on prejudice;
- Take all necessary legislative, administrative and other measures to ensure that all persons under arrest, regardless of their sexual orientation or gender identity, are entitled, on the basis of equality, to be informed of the reasons for arrest and the nature of any charges against them, and whether charged or not, to be brought promptly before a judicial officer and to bring court proceedings to determine the lawfulness of detention;
- Undertake programmes of training and awareness-raising to educate police and other law enforcement personnel regarding the arbitrariness of arrest and detention based on a person’s sexual orientation or gender identity; and
- Maintain accurate and up to date records of all arrests and detentions, indicating the date, location and reason for detention, and ensure independent oversight of all places of detention by bodies that are adequately mandated and equipped to identify arrests and detentions that may be motivated by the sexual orientation or gender identity of a person.

### Other Interpretations

**WG Arbitrary Detention:** The arrest and detention of men on the grounds that, by their sexual orientation, they incited ‘social dissention’ constitutes an arbitrary deprivation of liberty. The detention of people on the basis of their sexual orientation, even when the laws under which they are detained do not refer to homosexual conduct, violates human rights. E/CN.4/2003/8/Add.1, Opinion No. 7/2002 on Egypt, pg. 68.

**Code of Conduct for Law Enforcement Officials** (1979)

**Basic Principles on the Use of Force and Firearms by Law Enforcement Officials** (1990)

**Arab Charter on Human Rights**, art. 14(1). Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest, search or detention without a legal warrant.

## Table 8: LGBTI Health and Freedom of Assembly and Association

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• A government prohibits and criminalizes any associations for promotion of LGBTI rights, or refuses to register an LGBTI association.</li> <li>• A gay pride parade is banned by city authorities.</li> <li>• Police allow individuals opposing a LGBTI rights protest to commit violent acts against those protesting.</li> </ul>	
Yogyakarta Principle	
<p><b>Principle 20:</b> Everyone has the right to freedom of peaceful assembly and association, including for the purposes of peaceful demonstrations, regardless of sexual orientation or gender identity. Persons may form and have recognised, without discrimination, associations based on sexual orientation or gender identity, and associations that distribute information to or about, facilitate communication among, or advocate for the rights of, persons of diverse sexual orientations and gender identities.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>• Take all necessary legislative, administrative and other measures to ensure the rights to peacefully organise, associate, assemble and advocate around issues of sexual orientation and gender identity, and to obtain legal recognition for such associations and groups, without discrimination on the basis of sexual orientation or gender identity;</li> <li>• Ensure in particular that notions of public order, public morality, public health and public security are not employed to restrict any exercise of the rights to peaceful assembly and association solely on the basis that it affirms diverse sexual orientations or gender identities;</li> <li>• Under no circumstances impede the exercise of the rights to peaceful assembly and association on grounds relating to sexual orientation or gender identity, and ensure that adequate police and other physical protection against violence or harassment is afforded to persons exercising these rights;</li> <li>• Provide training and awareness-raising programmes to law enforcement authorities and other relevant officials to enable them to provide such protection; and</li> <li>• Ensure that information disclosure rules for voluntary associations and groups do not, in practice, have discriminatory effects for such associations and groups addressing issues of sexual orientation or gender identity, or for their members.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 21</b> The right of peaceful assembly shall be recognized. No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.</p> <p><b>ICCPR 22</b> Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests.</p>	<p><b>HRC General Comment 34:</b> Where States rely on restrictions to the right to freedom of assembly and association, they must ensure that the laws restricting the rights are compatible with the provisions, aims and objectives of the ICCPR and must not violate the non-discrimination provisions of the Covenant. CCPR/C/GC/34 (2011) at para 26.</p> <p><b>HRC:</b> recommending that <b>Russia</b> should “take all necessary measures to guarantee the exercise and practice of the right to peaceful association and assembly for the LGBT community.” CCPR/C/RUS/CO/6 (2009) at para. 27(c).</p>

**Table 8 (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 11(1)</b> Everyone has the right to freedom of peaceful assembly and to freedom of association with others, including the right to form and to join trade unions for the protection of his interests.</p> <p><b>ECHR 11(2)</b> No restrictions shall be placed on the exercise of these rights other than such as are prescribed by law and are necessary in a democratic society in the interests of national security or public safety, for the prevention of disorder or crime, for the protection of health or morals or for the protection of the rights and freedoms of others. This Article shall not prevent the imposition of lawful restrictions on the exercise of these rights by members of the armed forces, of the police or of the administration of the State.</p>	<p><b>ECtHR:</b> the Court held that refusal to grant permission for proposed demonstration on LGBT rights violated the Convention. <i>Genderdoc-M v. Moldova</i>, 9106/06 (June 12, 2012).</p> <p><b>ECtHR:</b> the Court held that banning the Pride March in 2006, 2007 and 2008 interfered with the applicant’s freedom of assembly guaranteed by the Convention. <i>Alekseyev v. Russia</i>, 4916/07, 25924/08, 14599/09 (Oct. 21, 2010).</p> <p><b>ECtHR:</b> the Court declared the ban on LGBT pride march in Warsaw in 2005 illegal and discriminatory. <i>Baczkowski and Others v. Poland</i>, 1543/06 (May 3, 2007).</p>

### Other Interpretations

**Special Representative of the Secretary-General on human rights defenders:** In numerous cases from all regions, police or government officials are the alleged perpetrators of violence and threats against defenders of LGBTI rights. In several of these cases, the authorities have prohibited demonstrations, conferences and meetings, denied registration of organizations working for LGBTI rights and police officers have, allegedly, beaten up or even sexually abused these defenders of LGBTI rights. The authorities have generally attempted to justify action against these defenders by arguing that “the public” does not want these demonstrations to take place, or these organizations need to be registered, or that “the people” do not want LGBTI people in their community. The Special Representative recalls articles 2 and 12 of the Declaration on Human Rights Defenders to remind States of their responsibility for protecting defenders against violence and threats. States are also responsible for, inter alia, ensuring that all programmes for training of law enforcement officers and public officials include appropriate elements of human rights teaching (art. 15). A/HRC/4/37 (2007) at para. 96.

**SR on contemporary forms of racism:** Laws that prohibit public promotion of homosexuality or homosexual propaganda may silence any discussion of sexuality in the public sphere. States should ensure that LGBTI marches, parades and other gatherings are not denied permits because of their sexual orientation or gender identity, and States should take steps to stop violence from spectators of such gatherings. E/CN.4/2006/16/Add.1 at para. 72.

**Special Representative of Human Rights Defenders, SR Racism, SR Violence against Women, and SR Health:** Laws that criminalize persons seeking same sex relationships and marriage, as well as organizations working on or speaking about such issues contravene the right to freedom of assembly and association. UN Press Release, Independent UN experts express serious concern over draft Nigerian bill outlawing same-sex relationships (HR/07/25), 23 February 2007.

## Table 9: LGBTI Health and Freedom of Expression and Information

### Examples of Human Rights Violations

- Young people are denied information about HIV and AIDS, safer sex, and condoms, as well as about sexual behaviors such as homosexuality.
- A state agency in charge of newspaper distribution refuses to distribute an LGBTI publication.
- A trans-gender student is forced by school authorities to dress according to his “biological sex.”

### Yogyakarta Principle

**Principle 19:** Everyone has the right to freedom of opinion and expression, regardless of sexual orientation or gender identity. This includes the expression of identity or personhood through speech, deportment, dress, bodily characteristics, choice of name, or any other means, as well as the freedom to seek, receive and impart information and ideas of all kinds, including with regard to human rights, sexual orientation and gender identity, through any medium and regardless of frontiers.

States shall:

- Take all necessary legislative, administrative and other measures to ensure full enjoyment of freedom of opinion and expression, while respecting the rights and freedoms of others, without discrimination on the basis of sexual orientation or gender identity, including the receipt and imparting of information and ideas concerning sexual orientation and gender identity, as well as related advocacy for legal rights, publication of materials, broadcasting, organisation of or participation in conferences, and dissemination of and access to safer-sex information;
- Ensure that the outputs and the organisation of media that is State-regulated is pluralistic and non-discriminatory in respect of issues of sexual orientation and gender identity and that the personnel recruitment and promotion policies of such organisations are nondiscriminatory on the basis of sexual orientation or gender identity;
- Take all necessary legislative, administrative and other measures to ensure the full enjoyment of the right to express identity or personhood, including through speech, deportment, dress, bodily characteristics, choice of name or any other means;
- Ensure that notions of public order, public morality, public health and public security are not employed to restrict, in a discriminatory manner, any exercise of freedom of opinion and expression that affirms diverse sexual orientations or gender identities;
- Ensure that the exercise of freedom of opinion and expression does not violate the rights and freedoms of persons of diverse sexual orientations and gender identities; and
- Ensure that all persons, regardless of sexual orientation or gender identity, enjoy equal access to information and ideas, as well as to participation in public debate.

**Table 9 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICCPR 21 (1)</b> Everyone shall have the right to hold opinions without interference.</p> <p><b>ICCPR 21 (2)</b> Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.</p> <p><b>ICCPR 21 (3)</b> The exercise of the rights provided for in paragraph 2 of this article carries with it special duties and responsibilities. It may therefore be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:</p> <ul style="list-style-type: none"> <li>(a) For respect of the rights or reputations of others;</li> <li>(b) For the protection of national security or of public order (ordre public), or of public health or morals.</li> </ul>	<p><b>HRC General Comment No. 34:</b> explaining that where States rely on restrictions to the right to freedom of expression and information, they must ensure that the laws restricting the rights are compatible with the provisions, aims and objectives of the ICCPR and must not violate the non-discrimination provisions of the Covenant. CCPR/C/GC/34 (2011) at para 26.</p> <p><b>HRC:</b> recommending that <b>Russia</b> “take all necessary measures to guarantee the exercise in practice of the right to peaceful association and assembly for the LGBT community.” CCPR/C/RUS/CO/6 (2009) at para 27.</p>
<p><b>CRC 13(1)</b> The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice.</p> <p><b>CRC 17</b> States Parties recognize the important function performed by the mass media and shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health.</p>	<p><b>CRC General Comment 3:</b> explaining that adolescent’s right to information about HIV and AIDS is part of the right to information. CRC/GC/2003/3 (2003) at para. 4.</p>

**Other Interpretations**

**SR Education:** “In order to be comprehensive, sexual education must pay special attention to diversity, since everyone has the right to deal with his or her own sexuality without being discriminated against on grounds of sexual orientation or gender identity. Sexual education is a basic tool for ending discrimination against persons of diverse sexual orientations.” A/65/162 (July 23, 2010), para. 22.

**SR Freedom of Expression and Information:** Has commented on or expressed concern about: the abuse of the rights of sex workers and LGBTI persons; restrictions on public speech and denial of HIV and AIDS information to these communities; detention of persons in Kuwait because of a letter mentioning a lesbian relationship, and the arrests and harassment of two gender-non-conforming women in Uganda.

**SR Human Rights Defenders, SR Racism, SR Violence against Women, and SR Health:** Collectively criticized a Bill in Nigeria that would criminalize persons seeking same sex relationships and marriage, as well as organizations working on or speaking about such issues (2007). HR/07/25 (FEB. 23, 2007). <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=5599&LangID=E>.



## Table 10: LGBTI Health and the Right to Marry and Found a Family

### Examples of Human Rights Violations

- A government refuses to accord to unmarried same-sex couples the same rights and responsibilities it accords to unmarried different-sex couples.
- A lesbian woman is denied the right to artificial insemination services.
- A single gay man is denied the right to adopt a child.

### Applicable Yogyakarta Principle

**Principle 24:** Everyone has the right to found a family, regardless of sexual orientation or gender identity. Families exist in diverse forms. No family may be subjected to discrimination on the basis of the sexual orientation or gender identity of any of its members.

States shall:

- Take all necessary legislative, administrative and other measures to ensure the right to found a family, including through access to adoption or assisted procreation (including donor insemination), without discrimination on the basis of sexual orientation or gender identity;
- Ensure that laws and policies recognise the diversity of family forms, including those not defined by descent or marriage, and take all necessary legislative, administrative and other measures to ensure that no family may be subjected to discrimination on the basis of the sexual orientation or gender identity of any of its members, including with regard to family-related social welfare and other public benefits, employment, and immigration;
- Take all necessary legislative, administrative and other measures to ensure that in all actions or decisions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration, and that the sexual orientation or gender identity of the child or of any family member or other person may not be considered incompatible with such best interests;
- In all actions or decisions concerning children, ensure that a child who is capable of forming personal views can exercise the right to express those views freely, and that such views are given due weight in accordance with the age and maturity of the child;
- Take all necessary legislative, administrative and other measures to ensure that in States that recognise same-sex marriages or registered partnerships, any entitlement, privilege, obligation or benefit available to different-sex married or registered partners is equally available to same-sex married or registered partners;
- Take all necessary legislative, administrative and other measures to ensure that any obligation, entitlement, privilege, obligation or benefit available to different-sex unmarried partners is equally available to same-sex unmarried partners;
- Ensure that marriages and other legally-recognised partnerships may be entered into only with the free and full consent of the intending spouses or partners.

**Table 10 (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 8</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><b>ECHR 14</b> The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.</p>	<p><b>ECtHR:</b> held Portugal's denial of custody rights to a biological father in a same-sex relationship violated the right to private life (Art. 8) in conjunction with the right to non-discrimination (Art. 14). <i>Salgueiro Da Silva Mouta v. Portugal</i>, 33290/96 (Dec. 21, 1999).</p> <p>ECtHR: held that the State cannot justify discrimination of unmarried same-sex couples by "protection of traditional family", thus saying that the State should give same rights to same-sex and different-sex unmarried couples. The Court held that there was a violation of Article 14 (right to non-discrimination) in conjunction with Article 8 (right to privacy). <i>Karner v. Austria</i>, 40016/98 (July 24, 2003).</p> <p><b>ECtHR:</b> found that the State's refusal to grant the applicant authorization to adopt was based upon considerations of the applicant's sexual orientation. The court held that this violated Article 14 in conjunction with Article 8. Case of <i>E.B. v. France</i>, 43546/02 (Jan. 22, 2008).</p> <p><b>ECtHR:</b> the effect of an adoption by the applicant's mother's co-habitant partner severed the mother-daughter relationship of the applicant because the mother and her male partner were not married. The Court held that the effect of the adoption violated the applicant's right to respect for their family life under Article 8. Case of <i>Emonet and Others v. Switzerland</i>, 39051/03 (Dec. 13, 2007).</p>
<p><b>ECHR 12</b> Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right.</p>	<p><b>ECtHR:</b> The applicant is a male-to-female transsexual and wished to marry a man. The Court considered under Art 12, whether the registering of gender at birth is a limitation impairing the right to marriage. The Court found no justification for barring transsexuals from enjoying the right to marriage and that there was a violation of Art. 12. Case of <i>Christine Goodwin v. The United Kingdom</i>, 28957/95 (July 11, 2002).</p>
<p><b>ACHR 5(1)</b> Every person has the right to have his physical, mental, and moral integrity respected.</p> <p><b>ACHR 11(1)</b> Everyone has the right to have his honor respected and his dignity recognized.</p>	<p><b>IACHR:</b> Concerning a lesbian mother denied custody of her daughters because of her sexual orientation. <i>Caso Atala Riffo y Nias vs. Chile</i>, Judgment of February 24, 2012. <a href="http://corteidh.or.cr/docs/casos/articulos/seriec_239_ing.pdf">http://corteidh.or.cr/docs/casos/articulos/seriec_239_ing.pdf</a>.</p>

**Other Interpretations**

**SR Human Rights Defenders, SR Racism, SR Violence against Women, and SR Health:** Collectively criticized a Bill in Nigeria that would criminalize persons seeking same sex relationships and marriage, as well as organizations working on or speaking about such issues (2007).—HR/07/25 (FEB. 23, 2007). <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=5599&LangID=E>

**Table II: LGBTI Health and the Right to Education**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>No information in school curriculum about LGBTI health/sexual health education for future protection against sexually transmitted illnesses such as HIV and AIDS. Sexual education should be broadened to include specific information about the health of LGBTI persons.</li> <li>LGBTI communities do not have access to opportunities and resources for lifelong knowledge because of discrimination based on their sexual orientation or gender identity. Secondary schooling does not provide information on LGBTI health issues, nor the equivalent of the preventative health education that is provided on heterosexual health.</li> <li>Secondary schools do not uphold LGBTI health education in their curriculum. As a result, LGBTI youth are not exposed to crucial information in regards to their health, which is necessary as a tool for their future growth and health.</li> </ul>

Yogyakarta Principle
<p><b>Principle 16:</b> Everyone has the right to education, without discrimination on the basis of, and taking into account, their sexual orientation and gender identity.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>Take all necessary legislative, administrative and other measures to ensure equal access to education, and equal treatment of students, staff and teachers within the education system, without discrimination on the basis of sexual orientation or gender identity;</li> <li>Ensure that education is directed to the development of each student's personality, talents, and mental and physical abilities to their fullest potential, and responds to the needs of students of all sexual orientations and gender identities;</li> <li>Ensure that education is directed to the development of respect for human rights, and of respect for each child's parents and family members, cultural identity, language and values, in a spirit of understanding, peace, tolerance and equality, taking into account and respecting diverse sexual orientations and gender identities;</li> <li>Ensure that education methods, curricula and resources serve to enhance understanding of and respect for, inter alia, diverse sexual orientations and gender identities, including the particular needs of students, their parents and family members related to these grounds;</li> <li>Ensure that laws and policies provide adequate protection for students, staff and teachers of different sexual orientations and gender identities against all forms of social exclusion and violence within the school environment, including bullying and harassment;</li> <li>Ensure that students subjected to such exclusion or violence are not marginalised or segregated for reasons of protection, and that their best interests are identified and respected in a participatory manner;</li> <li>Take all necessary legislative, administrative and other measures to ensure that discipline in educational institutions is administered in a manner consistent with human dignity, without discrimination or penalty on the basis of a student's sexual orientation or gender identity, or the expression thereof;</li> <li>Ensure that everyone has access to opportunities and resources for lifelong learning without discrimination on the basis of sexual orientation or gender identity, including adults who have already suffered such forms of discrimination in the educational system.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 13</b> The State Parties recognise the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms.</p>	<p><b>HRC [Jurisprudence]:</b> observing that “[c]riminalisation of homosexual activity would appear to run counter to the implementation of effective education programmes in respect of HIV/AIDS prevention.” <i>Toonen v. Australia</i>, HRC Communication No. 488/1992 (CCPR/C/50/D/488/1992).</p>

**Table II (cont.)**

Human Rights Standards	Case Law
<p><b>ESC 11</b> With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in cooperation with public or private organisations, to take appropriate measures designed inter alia:</p> <p><b>(2)</b> to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health.</p>	<p><b>ESCR:</b> finding “that certain specific elements of the educational material used in the ordinary curriculum are manifestly biased, discriminatory and demeaning, notably in how persons of non-heterosexual orientation are described and depicted .... These statements stigmatize homosexuals and are based upon negative, distorted, reprehensible and degrading stereotypes about the sexual behaviour of all homosexuals. ... In the context of the right to protection of health through the provision of sexual and reproductive health education as set out in Article 11§2, this positive obligation extends to ensuring that educational materials do not reinforce demeaning stereotypes and perpetuate forms of prejudice which contribute to the social exclusion, embedded discrimination and denial of human dignity often experienced by historically marginalised groups such as persons of non-heterosexual orientation. ... By permitting sexual and reproductive health education to become a tool for reinforcing demeaning stereotypes, the authorities have failed to discharge their positive obligation not to discriminate in the provision of such education, and have also failed to take steps to ensure the provision of objective and non-exclusionary health education.” Resolution CM/ResChS (2009) 7, Collective Complaint No. 45/2007, <i>International Centre for the Legal Protection of Human Rights (INTERIGHTS) v. Croatia</i>.</p>

**Other Interpretations**

**SR on the Right to Education:** Difficulties facing LGBTI youth are often aggravated by their sexual preferences. SR mentions cases of discrimination and exclusion where young girls have been dismissed permanently from educational institutions for displaying affections for same sex classmates.

**Table 12: LGBTI Health and the Right to Work**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• LGBTI individuals are not able to challenge employment decisions based on their sexual orientation and gender identity.</li> <li>• An LGBTI individual is dismissed, harassed or denied promotion as a result of their sexual orientation or gender identity.</li> <li>• The right to work with equal opportunities is denied to LGBTI persons because of their sexual orientation or gender identity.</li> </ul>	
Yogyakarta Principle	
<p><b>Principle 12:</b> Everyone has the right to decent and productive work, to just and favourable conditions of work and to protection against unemployment, without discrimination on the basis of sexual orientation or gender identity.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>• Take all necessary legislative, administrative and other measures to eliminate and prohibit discrimination on the basis of sexual orientation and gender identity in public and private employment, including in relation to vocational training, recruitment, promotion, dismissal, conditions of employment and remuneration;</li> <li>• Eliminate any discrimination on the basis of sexual orientation or gender identity to ensure equal employment and advancement opportunities in all areas of public service, including all levels of government service and employment in public functions, including serving in the police and military, and provide appropriate training and awareness-raising programmes to counter discriminatory attitudes.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 6</b> State Parties are to recognize the right to work, which includes the right of everyone to the opportunity to gain a living by work that he freely chooses or accepts.</p>	<p><b>CESCR General Comment No.18:</b> “The exercise of work in all its forms and at all levels requires direct consideration by each State party to the following:</p> <p>(i) Accessibility - The labour market must be open to everyone under its’ States’ jurisdiction.</p> <p>Under article 2(2) and article 3, the covenant prohibits any discrimination in access to and maintenance of employment on sexual orientation status, which has the intention or effect of impairing or nullifying exercise of the right to work on basis of equality.” E/C.12/GC/18 (2006).</p>

**Table 12 (cont.)**

Human Rights Standards	Case Law
<p><b>ECHR 8 (1)</b> Everyone has the right to respect for his private and family life, his home and his correspondence.</p> <p><b>(2)</b> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.</p>	<p><b>ECtHR:</b> Two of the applicants were employees of the Royal Navy and both were dismissed after their sexual orientation was made known to their employers. The applicants were dismissed pursuant to the Ministry of Defence's policy against homosexuals serving in the armed forces. The Court stated their dismissals constituted direct interferences with the applicants' right to respect for their private life. The status of the applicants' sexual orientation should not interfere with their right to work and be equal to others in employment. The Court concluded there was a violation of the ECHR article 8 in regard to each applicant. <i>Perkins and R. v. The United Kingdom</i>, 43208/98 and 44875/98 (October 22, 2002).</p>

**Other Interpretations**

**European Council, Council Directive establishing a General Framework for Equal Treatment in Employment and Occupation** [Equality Employment Framework Directive], 2000/78/EC (November 27, 2000).

<http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:en:HTML>.

(11) Discrimination based on religion or belief, disability, age or **sexual orientation** may undermine the achievement of the objectives of the EC Treaty, in particular the attainment of a high level of employment and social protection, raising the standard of living and the quality of life, economic and social cohesion and solidarity, and the free movement of persons.

(12) To this end, any direct or indirect discrimination based on religion or belief, disability, age or sexual orientation as regards the areas covered by this Directive should be prohibited throughout the Community. ...

(26) The prohibition of discrimination should be without prejudice to the maintenance or adoption of measures intended to prevent or compensate for disadvantages suffered by a group of persons of a particular religion or belief, disability, age or sexual orientation, and such measures may permit organisations of persons of a particular religion or belief, disability, age or sexual orientation where their main object is the promotion of the special needs of those persons.

## Table 13: LGBTI Health and the Right to Social Security

Examples of Human Rights Violations and failures to progressively realise the human right
<ul style="list-style-type: none"> <li>• Health benefits and insurances are not made available to LGBTI individuals, because of their sexual orientation or gender identity, including funds for body modifications.</li> <li>• Parental benefits must be equal and accessible to homosexual couples without any discrimination on the basis of their sexual orientation.</li> </ul>
Yogyakarta Principle
<p><b>Principle 13:</b> Everyone has the right to social security and other social protection measures, without discrimination on the basis of sexual orientation or gender identity.</p> <p>States shall:</p> <ul style="list-style-type: none"> <li>• Take all necessary legislative, administrative and other measures to ensure equal access, without discrimination on the basis of sexual orientation or gender identity, to social security and other social protection measures, including employment benefits, parental leave, unemployment benefits, health insurance or care or benefits (including for body modifications related to gender identity), other social insurance, family benefits, funeral benefits, pensions and benefits with regard to the loss of support for spouses or partners as the result of illness or death;             <ul style="list-style-type: none"> <li>• Ensure that children are not subject to any form of discriminatory treatment within the social security system or in the provision of social or welfare benefits on the basis of their sexual orientation or gender identity, or that of any member of their family;</li> <li>• Take all necessary legislative, administrative and other measures to ensure access to poverty reduction strategies and programmes, without discrimination on the basis of sexual orientation or gender identity.</li> </ul> </li> </ul>



### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>72</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>73</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>74</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>75</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>72</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>73</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>74</sup> Ibid.

<sup>75</sup> Ibid.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>76</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>76</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

## **4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS PROGRAMMING IN THE AREA OF LGBTI AND HEALTH?**

In this section, you are presented with five examples of human rights-based work in the area of LGBTI health and human rights. These are:

1. Gay rights advocacy in Romania
2. Lesbian right and women's rights in Namibia
3. Transgender rights in the Netherlands
4. Criminalization of same-sex sexual activity in Belize
5. The rights of children born with variations of reproductive or sexual anatomy in the US

## Example I: Gay rights advocacy in Romania

### Project Type

Advocacy

### The Organization

Formed in 1994, ACCEPT Association (ACCEPT) is the first LGBT (lesbian, gay, bisexual, transgender) nongovernmental organization to operate in Romania. Its mission is to “defend[] and promote the rights of LGBT in Romania as human rights.”

### The Problem

LGBT persons in Romania faced rampant discrimination and state-sponsored homophobia. With the support of religious and nationalist groups, the Romanian Penal Code penalized same-sex relations and associations (see Art. 200) with terms of imprisonment lasting from one to five years. One of the effects of the law was to drive same-sex activity underground and to impede HIV prevention and outreach efforts among men having sex with men.

### Actions Taken

Romanian and international groups working to protect the rights and health of LGBT persons developed a range of claims within European and international human rights frameworks. Specifically, they:

- Issued two major reports on LGBT rights in Romania, one by Human Rights Watch and the International Gay and Lesbian Human Rights Commission, and the other commissioned by UNAIDS.
- In 1995, ACCEPT was officially registered as a human rights nongovernmental organization. ACCEPT had to register as a human rights organization, not as an LGBT organization, because the law denied LGBT persons the right to freedom of assembly and association.
- Pressured Romania to conform to European Union and Council of Europe standards on non-discrimination on the basis of sexual orientation, as part of Romania’s process of accession to the EU.

## Conflict

**Romanian Penal Code Art. 200, law. No. 140/1996 (repealed 2001)** (prohibiting consensual same sex-conduct, as well as speech and associations promoting homosexual identity)

### European Convention on Human Rights

Article 8. Right to respect for private and family life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

### Results & Lessons Learned

- Romania’s admission to the Council of Europe on October 7, 1993 was predicated upon its abolishment of Art. 200, which was in violation of Art. 8 of the European Convention on Human Rights. After promising repeal of the Art. 200, Romania was granted admission to the Council of Europe in October 1993. Romania did not repeal Art. 200, but instead amended it, allowing continued prosecution of homosexuality. The Council, therefore, called once again upon Romania to change or repeal its law so as to bring Romania into compliance with the Convention. Also, the Council created two new special rapporteurs to make reports every six months “until all undertakings have been honored.”
- Prior to the change to the law, it was illegal for ACCEPT or other LGBT groups operating in Romania to engage in domestic gross root organizing because Article 200 denied LGBT populations the right to freedom of assembly and association. Therefore, ACCEPT and other similar LGBT organizations focused their energy on addressing the many human rights abuses against the LGBT populations in Romania, instead of community building exercises.
- ACCEPT successfully registered as a human rights group. While it was illegal to advocate for LGBT rights, it created alliances with other human rights groups working on freedom of expression and association. It was less successful at connecting with advocacy groups working on gender inequality, violence against women, and transgender rights.
- The penal code of Romania was amended in 2000 and further revised again in 2001. With guidance from the EU, Romania adopted a comprehensive anti-discrimination mechanism that included protection from discrimination on the grounds of both sexual orientation and HIV status.
- In 2004 ACCEPT organized the Festival of Diversity, the first Romanian gay festival and in 2005 it organized the first Gay Pride in Bucharest. Every year since, ACCEPT has hosted GayFest which is a Pride festival recognizing and celebrating diversity and includes Gay Prde. See, <http://www.gay-fest.ro/>.
- It was accession to the European Union on January 1, 2007, and pressure to prevent HIV/AIDS—especially when voiced by international agencies—that provided important leverage for reforming the penal law.
- Some religious and political leaders continue to foment anti-gay prejudice and violence. With the collapse of Communism in Eastern Europe, the influence of religion has risen. This is particularly true in Romania, where the Orthodox Church has powerful influence over the drafting of “moral” legislation, including those laws relating to LGBT populations.

### Additional Resources

- Human Rights Watch and the International Gay and Lesbian Human Rights Commission, *Public Scandals: Sexual Orientation and Criminal Law in Romania* (1998). [http://accept-romania.ro/images/stories/public\\_scandals.pdf](http://accept-romania.ro/images/stories/public_scandals.pdf).
- ACCEPT, *About us. Sexual minorities in Romania* (2003). [http://accept-romania.ro/images/stories/despre\\_noi\\_minoritati\\_sexuale\\_in\\_romania.pdf](http://accept-romania.ro/images/stories/despre_noi_minoritati_sexuale_in_romania.pdf) [Avaliable in Romani language only].

#### ACCEPT Association

Romania

E-mail: [irena@acceptromania.ro](mailto:irena@acceptromania.ro)

Web: <http://accept-romania.ro/>

## Example 2: Lesbian rights and women's rights in Namibia

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### Project Type

Advocacy

### The Organization

Sister Namibia is a nongovernmental organization (NGO) committed to gender and racial equality.

### The Problem

The elimination of all forms of discrimination against women, the protection of gender equality, and the promotion of women's health must include lesbian as well as heterosexual women. Yet it can be challenging to include lesbians in the women's movement, particularly when they are politically useful targets for politicians claiming to protect "national values."

### Actions Taken

In the Southern African country of Namibia, a network of women's organizations led by the NGO Sister Namibia included lesbian rights in a national Manifesto on women's rights. Many political attacks followed, but the network continued to advocate for lesbian rights as part of women's rights. Sister Namibia undertook a series of actions to include lesbian rights in their advocacy. Specifically, they:

- Included references to lesbian rights in a 90-page Manifesto on women's rights, following a broad national consultation beginning in 1999.
- Challenged numerous attacks by the dominant political party in Namibia, the South West African People's Organization (SWAPO), that lesbians and homosexuals are selfish, individualistic, and anti-Namibian.
- Continued to advance the rights of lesbians by, *inter alia*, creating a lesbian working group to work with Black women in townships, beginning a continent-wide Coalition of African Lesbians and exploring how the Women's Protocol to the ACHPR can be used to advance lesbian rights.

### Results & Lessons Learned

- The government attacks created more support for lesbian rights and increasing solidarity among women's rights and lesbian rights advocates. At workshops in rural areas, participants found new and creative arguments to defend the Manifesto and the rights of lesbians. But advocacy for lesbian rights has not attracted the same attention in Africa as advocacy against sodomy laws and for the rights of gay men.
- Lesbians become politically useful targets when governments—including some feminist-identified government officials who are anti-lesbian—wanted a target to blame while they were claiming to protect "African values."
- A founding member of *Sister Namibia* became a member of Parliament. But, the presidential and parliamentary elections held in November 2009 resulted in the re-election of President Hifikepune Pohamba and the continued rule of SWAPO. Violence based on sexual orientation and gender identity continues.



- The constitution and laws of Namibia protect freedom of association, and according to the U.S. Department of State's Annual Human Rights Report (2010), "the government generally respected this right in practice." The report goes on to find that, unlike the prior year, "[a] number of domestic and international human rights groups generally operated without government restriction, investigating and publishing their findings on human rights cases."
- Homophobia in Namibia is based, in part, on a fear of ethnic extinction. For instance, in a 2003 statement, President Nujoma declared that: "Homosexuality is against nature and our culture . . . . In Namibia we have a small population; we need to multiply." Political leaders in Namibia also breed fear of homosexual conversion. Also, they described homosexuality as European and distinctively not African.
- Collaboration between LGBT and feminist activists is almost unique to Namibia. Feminist groups in other African countries often do not collaborate with LGBT groups because feminists groups fear being discredited as un-African by nationalist leaders.
- Sister Namibia has, at times, struggled to find funding to support its continued operation. Obtaining domestic funding was difficult, given scarce resources and a SWAPO-led government that opposed LGBT rights. Sister Namibia, therefore, received a large share of its funding from Northern donors; but by April 2006, expectations that Sister Namibia would eventually be self-sustaining, combined with shifting priorities, led to reduced funding from Northern sources.

### **Sister Namibia**

Windhoek, Namibia

E-mail: [media@sisternamibia.org](mailto:media@sisternamibia.org)

Web: <http://www.sisternamibia.org/>

## Example 3: The rights of transgender persons in The Netherlands

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### **Project Type**

Advocacy

### **The Organisation**

Transgender Netwerk Nederland (TNN), 'works towards a gender-diverse society, for the emancipation of transgender people and for their well being as well as their relatives.'

### **The Problem**

The Netherlands generally has progressive policy with regards to the rights of gay and lesbian people. However, the focus on those who wish to change their gender has not been given the same level of attention. For this example, TNN focussed on the official requirement of forced sterilization of a person once they have undergone sex reassignment surgery.

### **Actions Taken**

TNN drew attention to the Government's endorsement of the Yogyakarta principles in relation to international LGBT policy. TNN highlighted the inconsistencies that existed in the government's policy decisions with regards to the rights of transgender persons and the Yogyakarta principles.

- TNN consulted with Ministry staff and parliamentarians from all parties and lobbied the Minister to abolish the requirement for forced sterilization. The Minister soon announced that the Government would bring the law in line with the Yogyakarta principles.
- After a period of inactivity on the issue, TNN took the opportunity to raise the issue again in 2008, when the Dutch Minister for Foreign Affairs was in New York for the presentation of a statement on sexual orientation, gender identity and human rights at the United Nations. In a move to shame the Ministry at a side event, the then Chair of TNN produced his passport proclaiming that he had had to prove sterilisation to get it and stating that the Minister should apply the Yogyakarta Principles domestically as well as internationally.

**Results & Lessons Learned**

- After these advocacy events, the Ministry announced that a change of law was imminent and wrote to TNN stating that a proposal would come to parliament by the end of 2009
- The relevant Ministry acknowledged its lack of knowledge on the issue of rights of transgender persons.
- It identifies that the initial aim of having forced sterilisation was to prevent children from having parents of the same gender, but this purpose is now redundant given the legalisation of same sex marriages.
- The Dutch Government adopted the Yogyakarta as a guide to its LGBTI policy, and then TNN was able to draw attention to the incoherency between the Government's domestic and international policy.
- This action also enabled the specifics of the Yogyakarta principles to be brought into Government for a more in depth discussion.
- However, the Netherlands has yet to introduce the new laws, and so sterilisation is still part of the requirements of a legal change in gender.

**Transgender Network Netherland (TNN)**

Amsterdam, Netherlands

E-mail: [info@transgendernetwerk.nl](mailto:info@transgendernetwerk.nl)

Web: <http://transgendernetwerk.nl/>

## Example 4: Criminality of same-sex sexual activity in Belize

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### Project Type

Advocacy

### The Organisation

United Belize Advocacy Movement (UNIBAM) is the only organisation in Belize working on issues of sexual orientation. Their work focuses mainly on HIV/AIDS prevention and access to treatment for men who have sex with men (MSM), as well as on advocacy for legal reform and public education to confront discrimination and homophobia in the country.<sup>77</sup>

### The Problem

The law of Belize criminalizes both private and public same-sex sexual activity punishable with imprisonment up to 10 years. Belizean law also prohibits prostitutes and homosexuals from immigrating to the country. Also, as defined in the criminal law, only women may be considered victims of rape and so men are not protected against it.

These laws, coupled with a society that is ridden with prejudice, discrimination, and police violence towards LGBTI persons, prevent men who have sex with men from accessing proper health care and prevention services in Belize.

### Actions Taken

In 2008, UNIBAM commissioned a report called *Show No Mercy: Barriers that Exist for Men who Have Sex with Men to Access Sexual and Reproductive Services*, which was targeted towards the National AIDS Commission (NAC). The focus of the report was not to lobby against the country's laws of criminalization of same sex activity in great length. Instead it focused on the negative health effects which derive from criminalisation, specifically the heightening rate of HIV infection and barriers to access of information on health. From this UNIBAM were able to make the argument that international law and public health mandated the repeal of the law against same-sex activity.

In 2010, the University of the West Indies Rights Advocacy Project (URAP) initiated the case with local senior counsel Lisa Shoman. Caleb Orozco and UNIBAM jointly filed suit with the Belize Supreme Court claiming that the criminalization of same sex activity violates the Belize Constitution which recognizes the right to human dignity, to be free from arbitrary or unlawful interference with one's privacy, and to equal protection under the law.

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<sup>77</sup> Yogyakarta principles in action, p 104

### Results & Lesson Learned

The 2008 report was written alongside the NAC process of legislative and policy review of HIV/AIDS prevention and treatment; aimed at highlighting the situation of MSM, and increasing access to treatment and prevention programs.

- The report identifies the Yogyakarta principles as complementary to public health principles, in a human rights framework.
- It highlights the basic claim that discrimination and stigma based on sexual orientation deny MSM the fundamental human right to the highest attainable standard of health.
- In incorporating the Yogyakarta principles in the report, human rights classes at the University of Belize have been able to demonstrate the breadth and provision of the principles within human rights law.

The case brought by Orozco and UNIBAM in 2010 is currently pending before the Court. While Orozco remains a complainant, UNIBAM has been removed as the second complainant and is now an interested party. Human Dignity Trust, Commonwealth Lawyers Association, and the International Commission of Jurists are also interested parties. A ruling on the case is expected anytime in 2013.

### Resources:

- Orozco C, *Show No Mercy: Barriers that Exist for Men who Have Sex with Men to Access Sexual and Reproductive Services* (UNIBAM and UNPF, February 2008). [http://ypinaction.org/files/01/25/No\\_Mercy.pdf](http://ypinaction.org/files/01/25/No_Mercy.pdf).
- Southern Poverty Law Center, *Dangerous Liaisons: The American Religious Right and the Criminalization of Homosexuality in Belize* (July 2013). [http://www.splcenter.org/sites/default/files/downloads/publication/dangerous\\_liaisons\\_full\\_report\\_o.pdf](http://www.splcenter.org/sites/default/files/downloads/publication/dangerous_liaisons_full_report_o.pdf).

#### United Belize Advocacy Movement (UNIBAM)

Belize

E-mail: [unibambusiness@gmail.com](mailto:unibambusiness@gmail.com)

Web: <http://unitedbelizeadvocacymovement.blogspot.com/>

## Example 5: The rights of children born with variations of reproductive or sexual anatomy in the US

### Project Type

Advocacy and Litigation

### The Organisation

Advocates for Informed Choice (AIC) is an organisation based in the US, which uses innovative legal strategies to advocate for the rights of children born with variations of reproductive or sexual anatomy.

### The Problem

Some children who are born with variations of reproductive or sexual anatomy undergo ‘corrective’ surgery to create an ostensible approximation of either male or female genitalia. The issue is that this non-consensual surgery can have devastating impacts on the child’s development, even when the child’s developing gender identity conforms to the surgical outcome.

### Actions Taken

AIC uses traditional legal and non-legal tools domestically and advocates internationally to protect the rights of children born with intersex conditions or “disorders of sex development” (DSD). On May 14th, 2013, Advocates for Informed Choice, with other affiliates, filed a lawsuit in South Carolina called *MC v. Aaronson*. The case is filed against various bodies and individual employees for performing an irreversible and medically unnecessary surgery on an infant who was in the state’s care at the time of the surgery.

### Results and Lessons Learned

The case is unresolved as of yet, however it should prove to be important for the rights of intersex persons regardless of the outcome as it highlights many relevant intersex issues:

- The case is important as it illustrates a radical shift in perspective about who is able to consent to what is done to intersex bodies, specifically during childhood.
- It highlights that although there may be actual health problems associated with some forms of intersex persons, this does not necessarily mean that being born with variations of reproductive or sexual anatomy is a medical problem.
- The case will raise awareness of intersex issues, and help shift the view away from a sensationalised and an often stigmatising point of view.
- As AIC also operates from an international advocacy standpoint, they will be able to use the findings and nuances of the case to further advocate for the rights of intersex persons. The case could create some useful guidance for other Countries when analysing similar issues.
- The case has already received attention from other sections of civil society, for example the Organisation Intersex International Australia (OII Australia) are following the case and anticipating the decision. Such a case could provide for some strong persuasive advocacy points for organisations similar to AIC on an international level.
- 10 days after *MC v. Aaronson* was filed another ground-breaking lawsuit was filed to protect an intersex child in Kenya. For more information, see: <http://www.the-star.co.ke/news/article-121590/intersex-child-5-sues-state-birth-certificate>.

### Additional Resources

- Resources on the case *MC v. Aaronson*:
  - o AIC blog post, with links to newspaper articles, available at: <http://aiclegal.org/aics-landmark-lawsuit-makes-history/>.
  - o Federal and state case complaints available at: <http://www.splcenter.org/get-informed/case-docket/mc-v-aaronson#.UZVREbVQGCK>.

#### **Advocates for Informed Choice**

California, United States

Web: <http://aiclegal.org/>

Facebook: [www.facebook.com/aicl原因](http://www.facebook.com/aicl原因)



## 5. WHERE CAN I FIND ADDITIONAL RESOURCES ON HEALTH AND HUMAN RIGHTS FOR LGBTI PERSONS?

A list of commonly used resources on health and human rights of LGBTI persons follows. It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Statements and Declarations
- D. LGBTI and Human Rights
- E. LGBTI and Discrimination
- F. LGBTI and the Right to Health
- G. Violence and Torture against LGBTI Persons
- H. Networks
- I. Websites

### A. International Instruments

- UN Commission on Human Rights, *Report of the Special Rapporteur, Nigel S. Rodley, on the question of the human rights of all persons subjected to any form of detention or imprisonment, in particular: torture and other cruel, inhuman or degrading treatment or punishment*, E/CN.4/1995/34 (January 12, 1995).
- UN Commission on Human Rights, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt*, E/CN.4/2004/49 (February 16, 2004).
- UN Committee Against Torture, *General Comment 2: Implementation of article 2 (prevention of acts of torture) by States parties*, CAT/C/GC/2 (January 24, 2008). <http://www2.ohchr.org/english/bodies/cat/comments.htm>.
- UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 14 on the right to the highest attainable standard of health*, E/C.12/2000/4 (August 11, 2000).
- UN General Assembly, *Report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment, Nigel S. Rodley*, A/56/156 (July 3, 2001). <http://www.un.org/documents/ga/docs/56/a56156.pdf>.
- UN Human Rights Council, *Human Rights, Sexual Orientation and Gender Identity*, A/HRC/RES/17/19 (July 14, 2011).
- UN Human Rights Council, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health: examining the relationship between the right to the highest attainable standard of health and the criminalization of same-sex conduct and sexual orientation, sex work, and HIV transmission*, A/HRC/14/20 (April 27, 2010). <http://www2.ohchr.org/english/bodies/hrcouncil/docs/14session/A.HRC.14.20.pdf>.

## B. Regional Instruments

- Council of Europe, *Council of Europe Convention on preventing and combating violence against women and domestic violence*, CETS No.: 210, Open for signature November 5, 2011 [Not entered into force as of July 29, 2013]. <http://www.conventions.coe.int/Treaty/EN/Treaties/Html/210.htm>.
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- Council of Europe, *Recommendation CM/Rec(2010)5 of the Committee of Ministers for member states on measures to combat discrimination on grounds of sexual orientation or gender identity* (March 31, 2010). <https://wcd.coe.int/ViewDoc.jsp?Ref=CM/Rec%282010%295&Language=lanEnglish&Ver=original&BackColorInternet=C3C3C3&BackColorIntranet=EDBo21&BackColorLogged=F5D383>.
  - Council of Europe, *Recommendation CM/Rec(2010)5 of the Committee of Ministers to member states on measures to combat discrimination on grounds of sexual orientation or gender identity – Explanatory Memorandum*, CM(2010)4 add 3 final (March 21, 2010). <https://wcd.coe.int/ViewDoc.jsp?id=1570957&Site=COE>.
- Council of Europe, *Committee on Equality and Non-Discrimination, Tackling discrimination on the grounds of sexual orientation and gender identity, Revised Memorandum* (March 15, 2013). [http://www.assembly.coe.int/Communication/aega17\\_2013.pdf](http://www.assembly.coe.int/Communication/aega17_2013.pdf).
- Council of Europe, *Parliamentary Assembly, Discrimination on the basis of sexual orientation and gender identity, Resolution 1728* (2010). <http://assembly.coe.int/Mainf.asp?link=/Documents/AdoptedText/ta10/ERES1728.htm>.
- *Council of Europe, Parliamentary Assembly, Discrimination on the basis of sexual orientation and gender identity, Recommendation 1915* (2010). <http://assembly.coe.int/Mainf.asp?link=/Documents/AdoptedText/ta10/EREC1915.htm>.
- *Council of Europe, Working Party on Human Rights, Toolkit to Promote and Protect the Enjoyment of all Human Rights by Lesbian, Gay, Bisexual and Transgender (LGBT) People*, 11179/10 (June 17, 2010). [http://eeas.europa.eu/human\\_rights/lgbt/docs/toolkit\\_en.pdf](http://eeas.europa.eu/human_rights/lgbt/docs/toolkit_en.pdf).
- *Council of the European Union, Guidelines to Promote and Protect the Enjoyment of All Human Rights by Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Persons* (June 24, 2013). [http://www.consilium.europa.eu/uedocs/cms\\_Data/docs/pressdata/EN/foraff/137584.pdf](http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/EN/foraff/137584.pdf).
- *European Parliament, Resolutions on Racism and Homophobia in Europe* (January 2006). [www.ilga.org/news\\_results.asp?FileID=736](http://www.ilga.org/news_results.asp?FileID=736).
- *European Union, Council Directive 2000/78/EC of 27 November 2000, establishing a general framework for equal treatment in employment and occupation* (November 27, 2000). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:en:HTML>.
- *Organisation of American States, Inter-American Convention Against All Forms of Discrimination and Intolerance*, AG/RES. 2804 (XLIII-O/13), (June 6, 2013). <http://www.oas.org/consejo/GENERAL%20ASSEMBLY/AG43regular.asp>.

## C. Other Statements and Declarations

- *Yogyakarta Principles: The Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity* (March 2007). <http://www.yogyakartaprinciples.org/>.
- International Conference on LGBT Human Rights, *The Montreal Declaration* (July 2006). [www.declarationofmontreal.org](http://www.declarationofmontreal.org).

- International Lesbian, Gay, Bisexual, Trans and Intersex Association, *ADEFRA Declaration: Violence Against Lesbian Women in Africa* (Oct. 20, 2006). [www.ilga.org/news\\_results.asp?LanguageID=1&FileCategoryID=1&FileID=901&ZoneID=4/](http://www.ilga.org/news_results.asp?LanguageID=1&FileCategoryID=1&FileID=901&ZoneID=4/).

## D. LGBTI and Human Rights

- Council of Europe, Commissioner for Human Rights, *Human Rights and Gender Identity* (July 29, 2009). <https://wcd.coe.int/ViewDoc.jsp?id=1476365>.
- Ettelbrick PL and Zerán AT, *The Impact of the Yogyakarta Principles on International Human Rights Law Development: A Study of November 2007 – June 2010* (September 10, 2010). [http://ypinaction.org/files/02/57/Yogyakarta\\_Principles\\_Impact\\_Tracking\\_Report.pdf](http://ypinaction.org/files/02/57/Yogyakarta_Principles_Impact_Tracking_Report.pdf).
- Heinze E, *Sexual Orientation – A Human Right: An Essay on International Human Rights Law* (Dordrecht: Martinus Nijhoff Publishers, 2005).
- International Commission of Jurists, *Sexual Orientation and Gender Identity in International Human Rights Law: The ICJ UN Compilation* (2013). [http://icj.wpengine.netdna-cdn.com/wp-content/uploads/2013/06/SOGI-UN-Compil\\_electronic-version.pdf](http://icj.wpengine.netdna-cdn.com/wp-content/uploads/2013/06/SOGI-UN-Compil_electronic-version.pdf).
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- International Commission of Jurists, *Sexual Orientation, Gender Identity and Justice: A Comparative Law Casebook* (Sep. 6, 2011). <http://www.icj.org/sexual-orientation-gender-identity-and-justice-a-comparative-law-casebook/>.
- International Commission of Jurists and the International Human Rights Program at the University of Toronto Faculty of Law, *Sexual Orientation and Gender Identity Legislative Database* (2013). <http://www.icj.org/sogi-legislative-database/>.
- International Conference on Human Rights, Sexual Orientation and Gender Identity, Oslo 15-16 April 2013, *Summary and Toolkit*. <http://www.hrsogi.org/pop.cfm?FuseAction=Doc&pAction=View&pDocumentId=48103>.
- International Gay and Lesbian Human Rights Commission, *Gender Expression and Human Rights* (April 30, 2007). <http://www.iglhrc.org/content/international-gender-expression-and-human-rights>.
- International Gay and Lesbian Human Rights Commission, *Intersexuality Is a Human Rights Issue* (April 30, 2007). <http://www.iglhrc.org/content/international-intersexuality-human-rights-issue>.
- International Gay and Lesbian Human Rights Commission, *Making the Mountain Move: An Activist's Guide to How International Human Rights Mechanisms Can Work for You* (Dec. 18, 2000). <http://www.iglhrc.org/binary-data/ATTACHMENT/file/000/000/179-1.pdf>.
- ILGA-Europe Reports: [http://www.ilga-europe.org/home/publications/reports\\_and\\_other\\_materials](http://www.ilga-europe.org/home/publications/reports_and_other_materials). Including:
  - *Rainbow Europe Map and Index* (January 2012).
  - *Human Rights and Gender Identity: Best Practice Catalogue* (December 2011).
  - *Toolkit for Training Police Officers on Tackling LGBTI-phobic crime* (October 2011).
  - *Annual Review: The Human Rights Situation of LGBTI People in Europe* (2011).
  - *6 steps to effective LGBT Human Rights Advocacy* (2010).

- O’Flaherty M and Fisher J, “Sexual Orientation, Gender Identity and International Human Rights Law: Contextualising the Yogyakarta Principles,” 8(2) *Human Rights Law Review* (2008): 207-248.
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- UN Free and Equal Campaign, Fact Sheets [*LGBT Rights: Frequently Asked Questions, International Human Rights Law, Equality and Non-Discrimination, Criminalization, Violence*]. <https://www.unfe.org/en/fact-sheets>.
- UN Office of the High Commissioner for Human Rights, *Born Free and Equal: Sexual Orientation and Gender Identity in International Human Rights Law* (2012). <http://www.ohchr.org/Documents/Publications/BornFree-AndEqualLowRes.pdf>.

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## E. LGBTI and Discrimination

- Council of Europe, *Combating discrimination on grounds of sexual orientation or gender identity: Council of Europe Standards* (June 2011). [http://www.coe.int/t/dghl/standardsetting/hrpolicy/Publications/LGBT\\_en.pdf](http://www.coe.int/t/dghl/standardsetting/hrpolicy/Publications/LGBT_en.pdf).
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  - *EU LGBT survey - European Union lesbian, gay, bisexual and transgender survey - Results at a glance* (May 2013)
  - *Homophobia, transphobia and discrimination on grounds of sexual orientation and gender identity in the EU Member States* (June 2011)
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  - *Homophobia and Discrimination on Grounds of Sexual Orientation in the EU Member States Part I – Legal Analysis* (June 2008)
- United Nations High Commissioner for Refugees, *Guidelines on International Protection NO.9: Claims to Refugee Status based on Sexual Orientation and/or Gender Identity within the context of Article 1A(2) of the 1951 Convention and/or its 1967 Protocol relating to the Status of Refugees* (October 23, 2012). <http://www.unhcr.org/509136ca9.pdf>.

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## F. LGBTI and the Right to Health

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- National Coalition for LGBT Health (US), *Guiding Principles for Lesbian, Gay, Bisexual and Transgender Inclusion in Health Care*. <http://lgbthealth.webolutionary.com/sites/default/files/LGBT%20Health%20Manifesto.pdf>.
- Open Society Foundations, *Transforming Health: International Rights-Based Advocacy for Trans Health* (February 2013). <http://www.opensocietyfoundations.org/reports/transforming-health>.
- Sheilds A, *Access to Health Care for LGBT People in Kyrgyzstan* (Open Society Foundations, July 2007). <http://www.opensocietyfoundations.org/reports/access-health-care-lgbt-people-kyrgyzstan>.
- The Knowledge for Health (K4Health) Project, *LGBTI Populations and HIV Prevention Toolkit* (last updated August 13, 2013). <http://www.k4health.org/toolkits/lgbti-hivprevention>.
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## G. Violence and Torture against LGBTI Persons

- Amnesty International, *Crimes of Hate, Conspiracy of Silence: Torture and Ill-Treatment based on Sexual Identity* (June 21, 2001). <http://www.amnesty.org/en/library/info/ACT40/016/2001>. [Available in English, Arabic, Spanish and French].
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- *In a Time of Torture: The Assault on Justice In Egypt's Crackdown on Homosexual Conduct* (March 2004). <http://www.hrw.org/reports/2004/02/29/time-torture-o>.
- *Lebanon: Stop Tests of Shame: Authorities Order Anal Examinations of Men Charged with Homosexuality* (August 10, 2012), <http://www.hrw.org/news/2012/08/10/lebanon-stop-tests-shame>.
- “Not Worth a Penny”: *Human Rights Abuses against Transgender People in Honduras* (May 29, 2009). <http://www.hrw.org/reports/2009/05/29/not-worth-penny-o>.
- *These Everyday Humiliations: Violence Against Lesbians, Bisexual Women, and Transgender Men in Kyrgyzstan* (October 6, 2008). <http://www.hrw.org/reports/2008/10/06/these-everyday-humiliations-o>.
- “They Hunt Us Down for Fun”: *Discrimination and Police Violence Against Transgender Women in Kuwait* (January 15, 2012). <http://www.hrw.org/reports/2012/01/15/they-hunt-us-down-fun>.
- “They Want Us Exterminated”: *Murder, Torture, Sexual Orientation and Gender in Iraq* (August 17, 2009). <http://www.hrw.org/reports/2009/08/17/they-want-us-exterminated-o>.
- *Together, Apart: Organizing around Sexual Orientation and Gender Identity Worldwide* (June 11, 2009). <http://www.hrw.org/reports/2009/06/10/together-apart>. “We are a Buried Generation”: *Discrimination and Violence against Sexual Minorities in Iran* (December 15, 2010). <http://www.hrw.org/reports/2010/12/15/we-are-buried-generation>.
- *Uganda: State Homophobia Threatens Health and Human Rights* (August 23, 2007). <http://www.hrw.org/news/2007/08/21/uganda-state-homophobia-threatens-health-and-human-rights>.
- “We Have the Upper Hand”: *Freedom of assembly in Russia and the human rights of lesbian, gay, bisexual and transgender people* (June 13, 2007). <http://www.hrw.org/reports/2007/06/13/we-have-upper-hand>.
- “We Need a Law for Liberation”: *Gender, Sexuality, and Human Rights in a Changing Turkey* (May 22, 2008). <http://www.hrw.org/reports/2008/05/21/we-need-law-liberation-o>.
- “We’ll Show You You’re a Woman”: *Violence and Discrimination against Black Lesbians and Transgender Men in South Africa* (2011), available at: <http://www.hrw.org/sites/default/files/reports/southafrica1211.pdf>.
- International Gay and Lesbian Human Rights Commission, *Violations of the Rights to Freedom of Expression, Assembly, and Association Related to Sexual Orientation, Gender Identity, and Gender Expression: A report prepared by the International Gay and Lesbian Human Rights Commission for the United Nations Special Rapporteur on the Promotion and Protection of the Right to Freedom of Opinion and Expression and the Special Representative of the Secretary General for Human Rights Defenders* (October 30, 2007). <http://www.iglhrc.org/sites/default/files/155-1.pdf>.
- TGUE, *Trans Murder Monitoring Project*. <http://www.tgeu.org/node/53>.
- UN Human Rights Council, *Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity: Report of the United Nations High Commissioner for Human Rights, A/HRC/19/41* (November 17, 2011). <http://www.ohchr.org/EN/Issues/Discrimination/Pages/LGBTUNReports.aspx>.

## H. Networks

- ARC International, SOGI listserv: <http://arc-international.net/network-development/sogi-listserv>.
  - “The SOGI list provides a space for global advocacy, focusing on discussions and strategies related to sexuality, sexual rights, sexual orientation, gender, gender identity and gender expression, and seeks to situate these discussions within a broader human rights framework.”

---

## I. Websites

- American Civil Liberties Union [United States]: <http://www.aclu.org/lgbt-rights>.
- ARC International: <http://arc-international.net>.
- The European Parliament’s Intergroup on LGBT Rights: <http://www.lgbt-ep.eu/>.
- Funders for LGBTQ Issues: <http://www.lgbtfunders.org/>.
- Human Rights Campaign [United States]: <http://www.hrc.org/>.
- Human Rights Watch, LGBT Rights: <http://www.hrw.org/topic/lgbt-rights>.
- Inter-American Commission on Human Rights, Unit on the Rights of Lesbian, Gay, Trans, Bisexual and Intersex Persons: <https://www.oas.org/en/iachr/lgtbi/default.asp>.
- International Commission of Jurists <http://www.icj.org/>
- International Gay and Lesbian Human Rights Commission (IGLHRC). [www.iglhrc.org](http://www.iglhrc.org).
- International Gay and Lesbian Youth Organization <http://www.iglyo.com/>
- International Lesbian, Gay, Bisexual, Trans and Intersex Association: <http://ilga.org/>.
- International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA) Europe: [www.ilga-europe.org](http://www.ilga-europe.org).
- International Lesbian, Gay, Bisexual, Transgender, Queer Youth and Student Organization: <http://www.iglyo.com/>.
- Russian LGBT Network. [www.lgbtnet.ru](http://www.lgbtnet.ru).
- Sexual Rights Initiative: <http://sexualrightsinitiative.com/>.
- Transgender Europe (TGEU): <http://www.tgeu.org/>.
- UN Free and Equal Campaign: <https://www.unfe.org/en>.
- UN Human Rights Council Panel on Sexual Orientation and Gender Identity (March 2012): <http://www.ohchr.org/EN/Issues/Discrimination/Pages/PanelSexualOrientation.aspx>.
- UN OHCHR, Combatting discrimination based on sexual orientation and gender identity: <http://www.ohchr.org/EN/Issues/Discrimination/Pages/LGBT.aspx>.



## 6. WHAT ARE KEY TERMS RELATED TO HEALTH AND HUMAN RIGHTS FOR LGBTI PERSONS?

### B

#### ***Bisexual***

Refers to an emotional, affective and sexual attraction to persons of both the same or a different sex/gender.

---

### C

**Criminalization** is the inclusion of same-sex relationships or related activities in the criminal legal code.

#### ***Cross Dresser***

Persons who, to different extents and with different regularity, dress in clothes traditionally ascribed to persons of the different sex. Transvestites may have a homosexual, heterosexual or bisexual orientation. Transvestites are sometimes called cross-dressers. See also transgender below.

---

### D

**Decriminalization** is the removal of same-sex relationships and related activities from the criminal legal code.

---

### G

#### ***Gay***

Can refer to either male or female-identified persons with homosexual orientations. In some cultural contexts the term gay only refers to male homosexuals.

#### ***Gender expression***

A broader term than gender identity, referring to masculine or feminine expressions such as dress, mannerisms, role-playing in private or social groups, or speech patterns. Gender expression is not always associated with a fixed gender identity and often changes.

#### ***Gender identity***

A personal identity each person creates from a deeply felt sense of being a man, a woman, or an identity spanning both or aspects of each, which may not correspond to the body. *Gender identity is distinct from sexual orientation.*

---

### H

#### ***Heterosexual***

Refers to an emotional, affective and sexual attraction to persons of a different sex/gender.

#### ***Homophobia***

Typically used in a disapproving sense to refer to policies and individuals who display fear, avoidance, prejudice, or condemnation of same-sex sexual practices or homosexuality in general.

**Homosexual**

Refers to an emotional, affective and sexual attraction to a person of the same sex/gender.

---

**I****Intersex**

Refers to a variety of conditions in which an individual is born with aspects of reproductive/sexual anatomy or physiology that do not fit the conventional assignment of having only a male or only female body.

---

**L****Lesbian**

While the term gay can refer to either male or female-identified persons with homosexual orientations, many prefer the term **lesbian** for homosexual women, in part to ensure women's visibility in LGBTI rights advocacy.

**LGBTI**

An acronym that groups together sexual orientation-based identities (lesbian, gay, bisexual) with a non-sexual orientation created category (transgender or transsexual and intersex). In some contexts and policy documents a broader acronym LGBTIQ or LGBTIQQ is used (intersex and queer and/or questioning).

---

**M****MSM (Men who have sex with men)**

A public health term describing any man who has sex with another man, whether occasionally, regularly, or as an expression of a gay identity. The term is meant to be *descriptive* without attaching an identity or meaning to the behaviour, so that health interventions—especially HIV/AIDS education and services—can be directed to persons on the basis of need. While useful, it can also be used to avoid or deny a right to an identity. Some men have begun to refer to themselves as “MSM,” suggesting the term is developing as an identity.

---

**Q****Queer**

A term often used to refer to LGBTI persons. Depending on the use, the term may be perceived as derisive or offensive, or as self-empowering.

**Questioning**

Refers to a person who is questioning their sexuality, gender, gender identity, or sexual orientation.

---

**S****Sex**

Refers to the biological characteristics that are used to define humans as female or male. Some individuals possess both female and male biological characteristics.

**Sexual health**

A state of physical, emotional, mental, and social well-being in relation to sexuality. Like health generally, it is not merely the absence of disease, but encompasses positive and complex experiences of sexuality as well as freedom to determine sexual relationships, as well as the possibility of having pleasurable sexual experiences, free of coercion, discrimination and violence.

**Sexual minorities**

A catch-all phrase referring to any group that adopts a sexual identity, gender identity, sexual orientation, or sexual behaviour that differs from a defined “majority.” Thus, in various cultural contexts, it may refer to homosexual or trans persons, or even persons who sell sex or practice sado-masochistic sex. It is always important to clarify which kind of people or practices are included in the “sexual minority” being referred to.

**Sexual orientation**

One of the components of sexuality distinguished by an enduring emotional, romantic, sexual or affectional attraction to individuals of a particular gender. Sexual orientation is different from sexual behavior because it refers to feelings and self-concept. Persons may or may not express their sexual orientation in their behaviors. The main terms used to describe sexual orientation are **homosexual, gay, lesbian, straight, and bisexual**.

**Sexual rights**

Human rights that are already recognized in national laws, international human rights documents and other consensus statements. Important sexual rights include the right to sexual and reproductive health services, sexuality education, respect for bodily integrity, rights of privacy and non-discrimination and expression that encompass the choice of sexual partner, consensual sexual relations, and consensual marriage without discrimination and the means to effect these decisions. *For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled.*

**Sexuality**

Consists of thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships related to sex, erotic desire. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

**T****Transgender**

Most commonly used as the umbrella term for people whose gender identity and/or gender expression differs from the sex they were assigned at birth. The term may include, but is not limited to: transsexuals, intersex people, cross-dressers, and other gender variant people. **Transgender** (or “trans”) persons are those who move across genders, meaning their gender identity may span identities associated with men or women, or change between the two. Transgender persons are sometimes but not always transsexual (see above): they may transition by medical means (altering their physiology or hormones), or by way of dress, roles, or behaviour. Trans people can have any sexual orientation.

**Transsexual (or “trans”)**

Individuals who identify with a different sex than that associated with the biological sex that was ascribed to them at birth. A transsexual person can be male-to-female or female-to-male. Transsexual persons can have a homosexual, heterosexual, or bisexual orientation.

# CHAPTER 9



## DISABILITY, COMMUNITY LIVING, HEALTH AND HUMAN RIGHTS

“ Disability is a human rights issue! I repeat: disability is a human rights issue. ”

— *Speech by Bengt Lindqvist, Special Rapporteur on Disability of the United Nations Commission on Social Development*

**Health and Human Rights Resource Guide**

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# INTRODUCTION

This chapter will introduce you to key principles of the Convention on the Rights of Persons with Disabilities (CRPD) and health and human rights issues facing persons with disabilities. The chapter will also introduce you the right of persons with disabilities to live in the community as well as the human rights violations against persons with disabilities living in institutions. This chapter is based upon the Convention on the Rights of Persons with Disabilities.

Some of the issues in this chapter are also addressed in Chapter 1 on Patient Care and Human Rights.

The chapter is organized into six sections that answer the following questions:

1. How is disability a human rights issue?
  - 1A. How is disability and health a human rights issue?
  - 1B. How is institutional living a human rights issue and what is community living?
2. What are the most relevant international and regional human rights standards related to disability, health and community living?
3. What is a human rights-based approach to advocacy, litigation, and programming related to disability, health and community living?
4. What are some examples of effective human rights-based work in the area of disability, health and community living?
5. Where can I find additional resources on disability and human rights?
6. What are key terms related to disability and human rights?

# I. DISABILITY AND HUMAN RIGHTS

## What do we mean by disability?

### Defining disability

The Convention on the Rights of Persons with Disabilities (“CRPD”) does not provide a definition of disability, but instead provides a broad description intended to be widely inclusive. The CRPD establishes in Article 1 that ‘persons with disabilities’ includes ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.<sup>1</sup> This description of disability shifts the focus toward the social and environmental barriers that hinder an individual’s participation in society rather than on the individual’s impairments.

This approach to disability is called the “social model” of disability. The “social model” recognizes that the exclusion of a person with a disability from society is the result of a barrier or hindrance to the individual’s ability to participate fully, rather than the result of the individual’s inherent inability to participate. For example, if a person cannot access a health clinic because of his/her mobility impairment, it is not his/her inability to walk which is the issue, but rather the clinic’s lack of accessibility.

### Global prevalence of disability

Persons with disabilities constitute a significant portion of the population worldwide, yet they remain one of the most marginalized and vulnerable populations. It is difficult to obtain accurate data on the number of people with disabilities worldwide because approaches to measuring disability vary across countries and according to the purpose and application of the data. However, the World Health Survey—a face-to-face household survey conducted in 2002-2004 in 59 countries—estimated that about 650 million adults had a disability, with about 92 million of those adults experiencing very significant disabilities.<sup>2</sup> The survey also demonstrated that the occurrence of disability is higher in low-income countries where about 18% of the population has a disability, in comparison to high income countries where about 11.8% of the population has a disability.<sup>3</sup>

### Human rights-based approach to disability

Over the past decade, awareness and understanding of issues related to disability rights has grown. In particular, the Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006 and entered into force on May 3, 2008, has been integral to advancing recognition of the human rights of persons with disabilities. The CRPD provides us with a comprehensive approach to realizing the rights of persons with disabilities.

1 United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 1 (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

2 World Health Organization, *World Report on Disability* (2011). [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf).

3 Id.

The CRPD is important for both outlining the rights of persons with disabilities and for changing perceptions of disability. The UN Office of the High Commissioner for Human Rights describes a human rights-based approach to disabilities:

*A rights-based approach seeks ways to respect, support and celebrate human diversity by creating the conditions that allow meaningful participation by a wide range of persons, including persons with disabilities. Protecting and promoting their rights is not only about providing disability-related services. It is about adopting measures to change attitudes and behaviours that stigmatize and marginalize persons with disabilities. It is also about putting in place the policies, laws and programmes that remove barriers and guarantee the exercise of civil, cultural, economic, political and social rights by persons with disabilities.<sup>4</sup>*

Persons with disabilities face wide-ranging human rights abuses including institutionalization, isolation, stigma and discrimination, and lack of access to health, education and employment opportunities. The CRPD sets out a wide range of rights that address all aspects of life, such as respect for home and the family, education, employment, health, participation in political and public life, participation in cultural life, recreation, leisure and sport, the right to life, freedom from torture or cruel, inhuman or degrading treatment or punishment and the right to equal protection and equal benefit of the law. The CRPD seeks to “ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.”<sup>5</sup>

## The CRPD and Conflicting Law

The CRPD is a relatively recent human rights treaty. The CRPD consolidates and expands on existing international law on the rights of persons with disabilities. As the UN Department of Public Information notes, “[the CRPD] does not create any ‘new rights’ or ‘entitlements’. What the convention does, however, is express existing rights in a manner that addresses the needs and situation of persons with disabilities.”<sup>6</sup>

The CRPD imposes new legal obligations on States and supersedes any prior non-binding international, regional or domestic standards. However, there are many binding regional and domestic standards that fall short of, or conflict with, the more recent and expansive CRPD standards. For example some standards and case law address forced treatment or confinement where due process was not maintained, but do not question the legitimacy of forced treatment or confinement. Likewise, some standards and case law qualify the right to live in the community, rather than protecting the right absolutely.

This chapter, including the tables, is based upon the CRPD and CRPD-aligned standards. The chapter does not include standards or case law that contravenes or diminishes the rights provided in the CRPD.

4 UN Office of the High Commissioner for Human Rights, *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors* (2010). [http://www.ohchr.org/Documents/Publications/Disabilities\\_training\\_17EN.pdf](http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf).

5 United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 1 (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

6 United Nations, *Convention on the Rights of Persons with Disabilities*, “Why a Convention?” <http://www.un.org/disabilities/convention/questions.shtml>.

# IA. HOW IS DISABILITY AND HEALTH A HUMAN RIGHTS ISSUE?

## Introduction

Using the CRPD as a framework, this section explores a human rights-based approach to health for persons with disabilities, including the social and economic determinants of health.

## The CRPD and the right to health

Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, under CRPD Article 25.<sup>7</sup> In this context, health is defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or illness.”<sup>8</sup> It is crucial to note that the CRPD establishes that disability is not necessarily a medical condition and emphasizes the role of environmental and attitudinal barriers, rather than an impairment (if it exists at all) in hindering full and effective participation in society on an equal basis with others. While persons with disabilities may at times need to access health services for medical conditions related to their disabilities, this should not be presumed to be their primary need for health services.

The right to health in Article 25 must be interpreted in the context of the core principles of CRPD outlined in Article 3. The core principles include non-discrimination; participation; autonomy, including the freedom to make one’s own choices; social inclusion; gender equality; and equality of opportunity. These principles are overarching and should guide interpretation of other CRPD articles.

## Progressive Realization and Non-Discrimination

The right to health established in Article 25 must also be read in light of Article 4(2) which requires States to progressively realize economic and social rights. Progressive realization means that “States parties have a specific and continuing obligation to move as expeditiously and effectively as possible”<sup>9</sup> towards the full realization of the right to health. The Committee on the Rights of Persons with Disabilities recognizes that no State is able to realize the right to health immediately. For example, States may have to develop health care infrastructure, train health professionals, or implement health care legal reforms to begin realizing the right to health. The obligation for States to progressively realize the right to health requires them to make continuing efforts to implement the right, recognizing that it is a process achieved over time.

States are immediately obligated, upon ratifying the CRPD, to ensure non-discrimination. The obligation to guarantee non-discrimination under the CRPD is the same as required under the ICESCR and the CRC, which “all impose an immediate obligation to guarantee that economic, social and cultural rights are enjoyed without discrimination. Accordingly, measures towards the progressive achievement of rights must at all times be guided by, and comply with, the basic requirement of non-discrimination.”<sup>10</sup> The obligation to guarantee non-discrimination must be immediately implemented “irrespective of the level of available

7 United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 25 (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

8 World Health Organization, “Definition of Health.” <http://www.who.int/about/definition/en/print.html>.

9 UN Nations Committee on Economic, Social, and Cultural Rights, *General Comment No. 3: The Nature of States Parties Obligations*, E/1991/23 (Dec. 14, 1990). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

10 United Nations Economic and Social Council (2007). “Report of the United Nations High Commissioner for Human Rights”, E/2007/82, 25 June. [http://ap.ohchr.org/documents/alldocs.aspx?doc\\_id=15584](http://ap.ohchr.org/documents/alldocs.aspx?doc_id=15584).

resources.”<sup>11</sup> The Committee on Economic, Social and Cultural Rights explains that non-discrimination is an immediate obligation for all States, regardless of resources because “many measures, such as most strategies and programmes designed to eliminate health-related discrimination, can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information.”<sup>12</sup>

## Access to Health Services

The CRPD requires that States Parties “take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.”<sup>13</sup> Persons with disabilities face a range of barriers in accessing health care services, including cost, accessibility, stigma and discrimination and lack of or inadequacy of services and resources.<sup>14</sup> Without equal access to health care, “people with disabilities are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation.”<sup>15</sup>

Both the CRPD and the Committee on Economic, Social and Cultural Rights (CESCR) provide guidance on what accessibility means and how it should be understood in the context of health. The CRPD broadly defines accessibility in Article 9 as “access, on an equal basis with others, to the physical environment, to transportation, to information and communications ... and to other facilities and services open or provided to public, both in urban and rural areas.”<sup>16</sup> CESCR explains in General Comment 14 on the right to health that the four components of accessibility are non-discrimination, physical accessibility, economic accessibility, and information accessibility.<sup>17</sup>

### Non-discrimination - Equal Access to Health Care

Non-discrimination is a central principle to the CRPD and is critical for ensuring equal access to health care for persons with disabilities. The CRPD defines in Article 2 that:

*“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.*<sup>18</sup>

All persons with disabilities have the same general health care needs as everyone else and require access to mainstream health care services on an equal basis as everyone else.<sup>19</sup> Also, with the move away from institutionalized living towards community living, it is crucial that health care services and facilities are developed and accessible to all persons with disabilities.

<sup>11</sup> Id.

<sup>12</sup> UN Nations Committee on Economic, Social, and Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health*, E/C.12/2000/4 (Aug. 11, 2000). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

<sup>13</sup> United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 25(a) (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

<sup>14</sup> World Health Organization, *World Report on Disability* (2011). [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf).

<sup>15</sup> Tomlinson M et al, “Health care and the UN Disability Rights Convention” *The Lancet*, 374, (Nov. 28, 2009).

<sup>16</sup> United Nations General Assembly, *Convention of the Rights of Persons with Disabilities*, A/RES/61/106, Art. 9(1) (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

<sup>17</sup> UN Nations Committee on Economic, Social, and Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health*, E/C.12/2000/4 (Aug. 11, 2000). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

<sup>18</sup> United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 2 (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

<sup>19</sup> World Health Organization, *Disability and health*, Fact Sheet (Nov 2012). <http://www.who.int/mediacentre/factsheets/fs352/en/index.html>.

**Physical Accessibility**

Physical accessibility is a critical component for ensuring equal access to health care for persons with disabilities. Physical barriers to accessing health care include both environmental and infrastructural barriers as well as geographical barriers, such as access to rural health centers.

The CESCR explains in General Comment 14 on the right to health that physical accessibility is defined as follows:

*Health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ... persons with disabilities ... Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities.*

The CRPD also focuses on geographical access to health care, establishing in Article 25(c) that States parties must “[p]rovide these health services as close as possible to people’s own communities, including in rural areas.” Provision of health care facilities to individuals in rural areas ensures that everyone is able to physically reach health care facilities. The provision of health services within an individual’s community is critical for persons with disabilities who have a right to access health services within their community.

In addition to access to health facilities, physical access extends to accessible medical equipment and services. For example, women with mobility impairments are often unable to access breast and cervical cancer screening because examination tables are not height-adjustable and mammography equipment only accommodates women who are able to stand.<sup>20</sup>

**Economic Accessibility**

The CRPD provides in Article 25 that States parties must “provide persons with disabilities the same range, quality and standard of free or affordable health care and programmes as provided to other persons ...” According to the 2002-2004 World Health Survey, affordability was the primary reason why persons with disabilities, across gender and age groups, did not receive needed health care in low-income countries.<sup>21</sup> In its study of 51 countries, the World Health Survey reported that 32–33% of nondisabled men and women cannot afford health care, compared with 51–53% of persons with disabilities.<sup>22</sup>

The CRPD establishes in Article 25 that States parties must “[p]rohibit discrimination against persons with disabilities in the provision of health insurance ... which shall be provided in a fair and reasonable manner.” However, persons with disabilities have lower rates of employment, making it more difficult for them to afford health insurance or less likely to be covered if health insurance is usually provided by the workplace. Those persons with disabilities who are provided health insurance may be denied coverage due to their pre-existing conditions or discriminatory coverage policies.

Affordable health insurance is an important measure for addressing barriers to financing and affordability. Measures can include targeting people with disabilities who have the greatest health care need, providing general income support, reducing or removing out of pocket payments to improve access, eliminating discriminatory provisions, and providing incentives to health providers to promote access.<sup>23</sup>

<sup>20</sup> Id.

<sup>21</sup> World Health Organization, *World Report on Disability* (2011). [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf).

<sup>22</sup> Id.

<sup>23</sup> Id.

### Information Accessibility

The form or the content of information can serve as barriers to accessing information for many persons with disabilities.<sup>24</sup> For example, presenting information in Braille and sign language are two different forms of communication which make information accessible to individuals who otherwise may experience barriers. Similarly, using easy-to-read language or using pictures and cartoons are different methods for changing the content of information to make it more accessible.

In the health context, access to information is crucial for patients to engage with their health care providers and to receive and understand relevant health information. Access to information in the health context extends to accessible forms, informational brochures and communication with health care providers. Access to information is also important for navigating the health care system. Information provided through referral systems, waiting lists or booking systems for appointments should also be accessible to everyone and facilities should also be outfitted with proper signage to and within buildings.

### Informed consent

The CRPD establishes in Article 25 that States parties must “[r]equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent ...” The UN Special Rapporteur on the right to health, Anand Grover, defines informed consent as the following:

*Informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers. Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well-being.*<sup>25</sup>

Informed consent is supported by the general principles in CRPD Article 3 which include individual autonomy and respecting the freedom of individuals to make decisions about their life.

Violations of informed consent may, in some instances, amount to torture. In his most recent report, the Special Rapporteur on torture, Juan Méndez, called on all countries to ban all non-consensual and forced medical interventions against persons with disabilities.<sup>26</sup> He explains that “Both this mandate and United Nations treaty bodies have established that involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment.”<sup>27</sup>

Persons with disabilities have the right to provide or withhold consent for any medical intervention or health service and should be involved and communicated with directly about their health. Health professionals should speak directly with individual them self about their health matters and health choices, and not speak solely to their carers, relatives or proxies.<sup>28</sup>

For more information on informed consent generally, please see Chapter 1 on Patient Care.

24 Office of the High Commissioner for Human Rights, *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors* (2010), pg. 58. [http://www.ohchr.org/Documents/Publications/Disabilities\\_training\\_17EN.pdf](http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf).

25 United Nations General Assembly, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, A/64/272 (Aug. 10, 2009).

26 Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb 2013). [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

27 Id.

28 Shakespeare T, Lezzoni LI, and Groce NE, “Disability and the training of health professionals,” *The Lancet* 374, no. 9704 (Nov. 28, 2009).



## Sexual and reproductive care of the same range, quality and standard of care as others

The CRPD establishes in Article 25 that States parties must provide persons with disabilities the same sexual and reproductive health care and programmes as provided to other persons. Sexual and reproductive rights must be guaranteed for persons with disabilities and yet persons with disabilities often experience gross violations of their rights and cannot access sexual and reproductive services. This quote from a guide on gender mainstreaming in public disability policies explains the content of sexual and reproductive rights respectively:

*Sexual rights, understood to mean liberty to decide freely and responsibly on all questions related to sexuality, implies also the right to exercise one's sexuality safely, free from discrimination, coercion and violence; the right to physical and emotional pleasure; the right to freely-chosen sexual orientation; the right to information on sexuality; and the right to access sexual health services. Reproductive rights, taken to mean the freedom and independence each individual has to decide responsibly if she or he wants to have children or not, how many, when and with whom, encompasses also the right to access information, education and the means to do so; the right to take decisions on reproduction free from discrimination, coercion and violence; the right to access quality primary healthcare, and the right to measures to protect motherhood. All these rights must be fully guaranteed for female adolescents and women with disabilities under conditions of equality, free consent and mutual respect: to date this has not been the case.<sup>29</sup>*

Statistics reveal that adolescents and adults with disabilities are more likely to be excluded from sexual and reproductive health education and face stigma, prejudice, and denial of access to sexual and reproductive health services.<sup>30</sup> It is commonly and wrongfully assumed that persons with disabilities are not sexually active and therefore do not need sexual and reproductive health information and services.

Women with disabilities often have their reproductive rights denied, and some are subjected to forced marriages, forced abortions and forced sterilizations.<sup>31</sup> Women with disabilities are particularly vulnerable to forced sterilizations that are performed under the auspices of legitimate medical care or the consent of others in their name.<sup>32</sup> Sterilization is defined as “a process or act that renders an individual incapable of sexual reproduction.” In his most recent report, the Special Rapporteur on torture, Juan Méndez, asserted that “forced abortions or sterilizations carried out by State officials in accordance with coercive family planning laws or policies may amount to torture.”<sup>33</sup> Forced sterilization of girls and women with disabilities is driven by social factors, including minimizing inconvenience to caregivers, the lack of adequate measures to protect against the sexual abuse and exploitation of women and girls with disabilities, and a lack of adequate and appropriate services to support women with disabilities in their decision to become parents. The International Federation of Gynecology and Obstetrics (FIGO) issued updated guidelines in 2011, reaffirming the rule of no

29 Ediciones CINCA, *Guide to gender mainstreaming in public disability policies* (Feb 2012): 246. <http://www.oea.org.at/inter-national/europaeische-union/europaeisches-und-internationales-recht/GuidetoGenderMainstreaminginPublicDisabilityPolicies.pdf#page=233>.

30 World Health Organization, *Disability and health*, Fact Sheet (Nov. 2012). <http://www.who.int/mediacentre/factsheets/fs352/en/index.html>; World Health Organization, *World Report on Disability* (2011). [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf).

31 Open Society Foundations, *Sterilization of Women and Girls: A Briefing Paper* (2011). <http://www.opensocietyfoundations.org/sites/default/files/sterilization-women-disabilities-20111101.pdf>; World Health Organization, *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA Guidance Note* (2009). [http://whqlibdoc.who.int/publications/2009/9789241598682\\_eng.pdf](http://whqlibdoc.who.int/publications/2009/9789241598682_eng.pdf).

32 Center for Reproductive Rights, *Reproductive Rights and Women with Disabilities* (2002). [http://www.handicap-international.fr/bibliographie-handicap/4PolitiqueHandicap/groupe-particuliers/Femmes\\_Genre/reproductive\\_rights.pdf](http://www.handicap-international.fr/bibliographie-handicap/4PolitiqueHandicap/groupe-particuliers/Femmes_Genre/reproductive_rights.pdf).

33 Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb 2013). [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

sterilization without informed consent of the women herself (that of a family member or guardian does not amount to consent,) and requiring both the provision of information in accessible formats and the time and support to make a decision.<sup>34</sup>

## Quality health care services and provision of specialized services

The CRPD establishes in Article 25 that States parties must “provide persons with disabilities with the same range, quality and standard of free or affordable health care programmes as provided to other persons.” Research demonstrates that persons with disabilities receive poorer health care services and consequently experience poorer health outcomes. Persons with disabilities are also more vulnerable to deficiencies in healthcare services, which increase their risk of secondary conditions, co-morbid conditions and age-related conditions.

For example, women with disabilities receive less screenings for breast and cervical cancer than women without disabilities, and people with intellectual impairments and diabetes are less likely to have their weight checked.<sup>35</sup> The Disability Rights Commission in the UK conducted a formal investigation into inequalities in health and found “that people with mental illness and people with intellectual impairments not only experienced more ill-health, but received a poorer service from health professionals and as a consequence they had higher rates of morbidity and mortality.”<sup>36</sup>

People with disabilities have the same healthcare needs as everyone else, especially as they age, and require screening, preventive, and wellness-oriented care as provided to other persons. Health care providers must be taught that “having a disability is not incompatible with being healthy and it should not be assumed that the issue for which consultation is being sought is related to disability.”<sup>37</sup>

Measures for addressing barriers to service delivery include: targeting interventions to complement inclusive health care, including people with disabilities in general health care services, improving access to specialist health services, providing people-centered health services, coordinating services and using information and communication technologies.<sup>38</sup>

## Health professionals

The CRPD establishes in Article 25 that States parties must “[r]equire health professionals to provide care of the same quality to persons with disabilities as to others ... by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.” States must also address human resource barriers to quality healthcare for people with disabilities by integrating disability education into undergraduate training, providing health care workers with continuing education, and supporting health care workers with adequate resources.<sup>39</sup>

34 International Federation of Gynecology and Obstetrics, *Female Contraceptive Sterilization* (June 2011). [http://www.wunrn.com/news/2011/06\\_11/06\\_27/062711\\_female.htm](http://www.wunrn.com/news/2011/06_11/06_27/062711_female.htm).

35 World Health Organization, *Disability and health* (June 2011). <http://www.who.int/mediacentre/factsheets/fs352/en/index.html>.

36 Shakespeare T, Lezzoni LI, and Groce NE, “Disability and the training of health professionals,” *The Lancet* 374, no. 9704 (Nov. 28, 2009).

37 Id.

38 World Health Organization, *World Report on Disability* (2011). [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf).

39 Id.

The CRPD prioritizes health care training and awareness as well as the creation of ethical standards in an effort to ensure that health professionals provide the same quality of care to persons with disabilities as to others. Health care education on disability should include a range of topics including clinical information, communication strategies and an introduction to a human rights approach to disability. Training beyond clinical information is important as explained in this article:

*Doctors and other health professionals who encounter disabled people in their professional practice should be aware not only of the causes, consequences, and treatment of disabling health conditions, but also of the incorrect assumptions about disability that result from stigmatised views about people with disabilities that are common within society... it is important for professionals to understand not just disease, but also the experience of living with disability.<sup>40</sup>*

Health care professional training on the rights of persons with disabilities combats stigma and equips providers with the awareness necessary to provide persons with disabilities quality health care.

## Social determinants of health and persons with disabilities

In General Comment 14, CESCR explains that the right to health is “an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.”<sup>41</sup> In addition to access to services, the right to health encompasses social factors that affect health, including gender equality, health-related education and information, and adequate nutrition.<sup>42</sup> Moreover, CESCR explains that the determinants of health must also be physically accessible, economically affordable, available in sufficient quantity and provided in a non-discriminatory manner.<sup>43</sup>

The determinants of health, as described above, “are in turn shaped by a wider set of forces: economics, social policies, and politics.”<sup>44</sup> Michael Marmot explains that “material deprivation is not simply a technical matter of providing clean water or better medical care. Who gets these resources is socially determined.”<sup>45</sup> Persons with disabilities, as a marginalized population, are more vulnerable to the social and economic determinants of health and consequently experience poorer health outcomes. As Richard Wilkinson and Michael Marmot explain, “It’s not simply that poor material circumstances are harmful to health; the social meaning of being poor, unemployed, socially excluded, or otherwise stigmatized also matters.”<sup>46</sup>

<sup>40</sup> Shakespeare T, Lezzoni LI, and Groce NE, “Disability and the training of health professionals,” *The Lancet* 374, no. 9704 (Nov. 28, 2009).

<sup>41</sup> UN Nations Committee on Economic, Social, and Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health*, E/C.12/2000/4 (Aug. 11, 2000). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

<sup>42</sup> Tomlinson et al, “Research Priorities for health of people with disabilities: an expert opinion exercise,” *The Lancet* 374 (Nov. 28, 2009).

<sup>43</sup> UN Nations Committee on Economic, Social, and Cultural Rights, *General Comment No. 14: The Right to the Highest Attainable Standard of Health*, E/C.12/2000/4 (Aug. 11, 2000). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.

<sup>44</sup> World Health Organization, “Social determinants of health: Key concepts.” [http://www.who.int/social\\_determinants/thecommission/finalreport/key\\_concepts/en/index.html](http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/index.html).

<sup>45</sup> Marmot M, “Social determinants of health inequities,” *The Lancet* 365 (2005): 1099–104. [http://www.who.int/social\\_determinants/strategy/Marmot-Social%20determinants%20of%20health%20inqualities.pdf](http://www.who.int/social_determinants/strategy/Marmot-Social%20determinants%20of%20health%20inqualities.pdf).

<sup>46</sup> Wilkinson R and I Marmot M, *Social determinants of health: the solid facts* (WHO Europe, 2003). [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0005/98438/e81384.pdf](http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf).

Persons with disabilities are “disproportionately poor, and have historically experienced diverse forms of social exclusion.”<sup>47</sup> For example, the Special Rapporteur on Health wrote that “Services to ensure the underlying determinants of health, includ[e] adequate sanitation, safe water and adequate food and shelter. Persons with mental disabilities are disproportionately affected by poverty, which is usually characterized by deprivations of these entitlements.”<sup>48</sup> Therefore, “Inclusive health-care models will be key tools for governments creating poverty-reduction programmes due to the link between disability and poverty.”<sup>49</sup>

The social and economic determinants of health for persons with disabilities are essential to consider. “Injustices occur when disability is overmedicalised. Seeing difficulties purely as individual problems can ignore structural issues that contribute to health status, such as poverty, environmental barriers, and social exclusion.”<sup>50</sup> A human rights-based approach that addresses the social and economic determinants of health, including discrimination, is required to address the persistent inequalities of persons with disabilities in health status and access to health care.

## Right to Education

Education is a social determinant of health, and lack of education can limit the enjoyment of the right to health and other economic and social rights. Generally, lower levels of education are associated with poorer health outcomes including illness, malnutrition and higher rates of infant mortality. It is important to consider access to education and quality education as part of the broader picture of health.

The CRPD provides in Article 24 that persons with disabilities must not be excluded from the general education system. States parties must enact legislation and implement policies to develop inclusive education systems. The CRPD establishes that when free primary education is provided, people with disabilities may not be excluded on the basis of their disability. When developing inclusive education systems, governments must also account for additional funding requirements and allocate appropriate funds from the budget.

The CRPD establishes that State parties must provide persons with disabilities the support necessary to facilitate their effective education. However, many schools do not facilitate education for persons with disabilities, thereby creating barriers to academic and social development. Barriers to effective education are diverse and include curriculum and pedagogy issues, inadequate training and support of teachers, physical inaccessibility, and labelling, violence, bullying, abuse and attitudinal problems.<sup>51</sup> The CRPD explains that States shall provide effective individualized support measures to maximize academic and social development. Societal attitudes of stakeholders, including teachers, school administrators and other students are also an important factor in facilitating equal education for persons with disabilities.<sup>52</sup>

47 Shakespeare T, Lezzoni LI, and Groce NE, “Disability and the training of health professionals,” *The Lancet* 374, no. 9704 (Nov. 28, 2009).

48 United Nations Economic and Social Council, *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, E/CN.4/2005/51 (Feb. 11, 2005).

49 Stein MA, “Health care and the UN Disability Rights Convention,” *The Lancet*, 374 (Nov. 28, 2009).

50 Shakespeare T, Lezzoni LI, and Groce NE, “Disability and the training of health professionals,” *The Lancet* 374, no. 9704 (Nov. 28, 2009).

51 World Health Organization, *World Report on Disability* (2011). [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf).

52 Id.

## Right to Work and Employment

The right to work and employment is also a social determinant of health and must be considered in the broad picture of health. Persons with disabilities have low participation in the labor market and, when employed, are frequently employed in low-paying positions.<sup>53</sup> It is not surprising that as a result, persons with disabilities are disproportionately poor and socially marginalized. Work is a means to gain a living as well as participate in one's community. The CRPD provides in Article 27 that persons with disabilities have the right to work on an equal basis with other, including the "right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities."<sup>54</sup>

Persons with disabilities face a range of barriers to employment opportunities, most significantly discrimination and stigma, lack of accommodation, lack of accessible transport, and denial of education and/or vocational training.<sup>55</sup> The CRPD guides States parties to focus on non-discrimination laws, accessibility, reasonable accommodation, and positive measures as means to implement the right to work for persons with disabilities.

## Violations of the right to health

### Freedom from Violence, Abuse and Exploitation<sup>56</sup>

Persons with disabilities are vulnerable to violence, abuse and exploitation, especially when persons with disabilities are reliant upon others for support and care. Persons with disabilities are susceptible to violations within their home and by family members, caregivers, health care professionals and community members.<sup>57</sup> People with disabilities also experience higher rates of corporal punishment in schools.<sup>58</sup> Persons with disabilities are also vulnerable to sexual violence, sexual abuse and sexual exploitation, and are up to three times more likely than non-disabled people to face physical and sexual abuse and rape.<sup>59</sup>

CRPD Article 16 on freedom from violence, abuse and exploitation provides detailed directives for countries on legislation, programs, monitoring systems and other measures to prevent and address violence against persons with disabilities. Under the CRPD, States parties must implement recovery and reintegration programs for persons with disabilities who were victims of violence, abuse or exploitation. Even though persons with disabilities are more vulnerable to violence, abuse and exploitation, they face barriers to accessing physical, cognitive and psychological rehabilitation services and legal interventions.

53 United Nations Human Rights Council, *Report of the Office of the United Nations High Commissioner for Human Rights: Thematic study on the work and employment of persons with disabilities*, A/HRC/22/25 (Dec. 17, 2012). <http://www.ohchr.org/EN/Issues/Disability/Pages/UNStudiesAndReports.aspx>.

54 United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 27 (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

55 United Nations Human Rights Council, *Report of the Office of the United Nations High Commissioner for Human Rights: Thematic study on the work and employment of persons with disabilities*, A/HRC/22/25 (Dec. 17, 2012). <http://www.ohchr.org/EN/Issues/Disability/Pages/UNStudiesAndReports.aspx>. See also, O'Reilly A, *The Right to decent work of persons with disabilities* (International Labour Organization, Nov. 30, 2007). [http://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/---publ/documents/publication/wcms\\_091349.pdf](http://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/---publ/documents/publication/wcms_091349.pdf).

56 United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 16 (2006). <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>.

57 United Nations General Assembly, *Note by the Secretary-General on Torture and other cruel, inhuman or degrading treatment or punishment*, A/63/175 (July 28, 2008).

58 Human Rights Watch, *US: Students with Disabilities Face Corporal Punishment at Higher Rates: ACLU and Human Rights Watch Seek Ban on Physical Discipline at School* (Aug. 10, 2009). <http://www.hrw.org/news/2009/08/07/us-students-disabilities-face-corporal-punishment-higher-rates>.

59 United Nations Population Fund, *Emerging Issues: Sexual and Reproductive Health of Persons with Disabilities*. [http://www.unfpa.org/upload/lib\\_pub\\_file/741\\_filename\\_UNFPA\\_DisFact\\_web\\_sp-1.pdf](http://www.unfpa.org/upload/lib_pub_file/741_filename_UNFPA_DisFact_web_sp-1.pdf).

## Freedom from Torture

In his most recent report, the Special Rapporteur on torture, Juan Méndez, writes that persons with disabilities are vulnerable to torture in the health care setting. The report affirms that involuntary and forced medical treatment in as well as involuntary commitment to health-care facilities and institutions are forms of torture and ill-treatment. He writes that “in the context of health care, choices by people with disabilities are often overridden based on their supposed “best interests”, and serious violations and discrimination against persons with disabilities may be masked as “good intentions” of health professionals.”<sup>60</sup> The report explains that violations cannot be justified by claims of “medical necessity,” and emphasizes the fundamental need for free, full, and informed consent by patients for any medical procedures.<sup>61</sup>

The following examples have been recognized by the Special Rapporteurs on torture, Méndez and Nowak, as forms of torture in the health care setting. All of these practices are prohibited under the CRPD<sup>62</sup> but may rise to the level of torture in the following circumstances:

- Forced and non-consensual medical interventions including:
  - o Forced administration of psychiatric medication without free and informed consent or against the individual’s will, under coercion or as a form of punishment. Also, “[t]he administration of drugs, such as neuroleptics, which cause trembling, shivering, and contractions, and make the individual apathetic and dull his or her intelligence has been recognized as a form of torture.”<sup>63</sup>
  - o Medical experimentation or medical treatments without consent including abortion, sterilization, electroshock treatment and psychosurgery.
  - o The use of electroshock treatment (also a form of forced and non-consensual medical interventions). In writing about prisoners, the Special Rapporteur explained that “unmodified ECT may inflict severe pain and suffering and often leads to medical consequences, including bone, ligament and spinal fractures, cognitive deficits and possible loss of memory. It cannot be considered as an acceptable medical practice, and may constitute torture or ill-treatment.”<sup>64</sup>

60 Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb 2013). [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

61 Guterma L, *Top UN Expert on Torture Demands an End to Abuse in Health Care* (Open Society Foundations, March 2013). <http://www.opensocietyfoundations.org/voices/states-must-end-abuses-health-care-demands-top-un-expert-torture>.

62 Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb 2013). [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

63 United Nations General Assembly, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Manfred Nowak, A/63/175 (July 28, 2008).

64 Id.



- o The use of restraints or seclusion for both long and short-term application (also a form of forced and non-consensual medical interventions). There have been reports of persons with disabilities tied, chained or handcuffed to their beds or chairs for prolonged periods.<sup>65</sup> Overmedication may also be considered a form of chemical restraint. The Special Rapporteur writes that “[i]t is important to note that “prolonged use of restraint can lead to muscle atrophy, life-threatening deformities and even organ failure, ‘and exacerbates psychological damage.’” The Special Rapporteur notes that there can be no therapeutic justification for the prolonged use of restraints, which may amount to torture or ill-treatment.”<sup>66</sup>
- Deprivation of liberty through involuntary commitment to psychiatric hospitals or institutions. “Deprivation of liberty that is based on the grounds of a disability and that inflicts severe pain or suffering could fall under the scope of the Convention against Torture (A/63/175, para. 65). In making such an assessment, factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account.”<sup>67</sup>

The Special Rapporteur against torture notes that all of the above practices are banned under the CRPD. States are urged to prohibit all forced and non-consensual medical treatment and to require the free and informed consent of patients prior to performing medical treatment.<sup>68</sup> As well, the Special Rapporteur against torture recommends that States abolish “[l]egislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent” citing to Article 14(1)(b) of the CRPD which provides that “the existence of a disability shall in no case justify a deprivation of liberty.”<sup>69</sup> Instead, the Special Rapporteur recommends that States “[r]eplace forced treatment and commitment by services in the community” that “meet needs expressed by persons with disabilities and respect the autonomy, choices, dignity and privacy of the person concerned...”<sup>70</sup>

65 United Nations General Assembly, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175* (July 28, 2008); Human Rights Watch, *Like a Death Sentence: Abuses Against People with Mental Disabilities in Ghana* (Oct. 2012). <http://www.hrw.org/reports/2012/10/02/death-sentence-0>; Tavanier YB, *Institutions Remain Dumping Grounds for Forgotten People*, Newsletter (European Coalition for Community Living, 2009). <http://www.opensocietyfoundations.org/publications/institutions-remain-dumping-grounds-forgotten-people>.

66 United Nations General Assembly, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175* (July 28, 2008).

67 Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53* (Feb 2013). [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

68 Id.

69 Id.

70 Id.



## IB. HOW IS INSTITUTIONAL LIVING A HUMAN RIGHTS ISSUE AND WHAT IS COMMUNITY LIVING?

### Introduction

This section focuses on CRPD Article 19 on the right of persons with disabilities to live independently and to be included in the community. CRPD Article 19 provides that persons with disabilities have the right to live in the community and to participate in society as equal citizens. This right is referred to as “the right to community living” within this chapter. The right to community living reinforces that persons with disabilities are not restricted in their choices and opportunities because of their own limitations, but rather are restricted as a result of social and physical environmental barriers to their full and equal participation within their communities. The focus of community living is to create an enabling social and physical environment so that all persons are able to be included and participate in their community.

This section will begin by discussing violations of Article 19 on community living, focusing on segregation in institutions as well as isolation in the community, including in group home and home living arrangements. Additional human rights violations that occur in institutions including heightened risk of exploitation, violence and abuse and will also be explored in the first section. The chapter will then examine the right to community living and how this right may be implemented. As states move away from institutionalized living, it is important to understand what alternatives are available that respect the right to community living.

The analysis in this section of the chapter is based solely upon CRPD Article 19.

### How is institutional living a human rights issue?

#### Institutionalization violates the right to community living

Persons with disabilities are frequently segregated in institutions against their will where they are denied the opportunity to make decisions about their lives or participate in the community as equal citizens. Persons with disabilities are often deprived of their right to live independently and instead are placed in residential institutions—a process known as “institutionalization.” The term ‘institutionalization’ is used to describe a person with a disability who has been confined to an institution, often against their will, and deprived of the ability to make decisions about their lives.

The most common conception of an institution is a large, long-term residence facility. However, rather than focus upon a set of defining characteristics of institutional residences, human rights advocates focus on the culture of institutions and their effect upon the individual as portrayed in the following description:

*An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and day to day decisions. An institution is not defined merely by its size.<sup>71</sup>*

<sup>71</sup> Parker C and Clements L, *The European Union and the Right to Community Living: Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities* (Open Society Foundations, 2012). <http://www.opensocietyfoundations.org/sites/default/files/europe-community-living-20120507.pdf>; European Coalition for Community Living, *Wasted Time, Wasted Money, Wasted Lives—A Wasted Opportunity?*, Focus Report (2010): 78. <http://community-living.info/documents/ECCL-StructuralFundsReport-final-WEB.pdf>; Inclusion International, *Inclusion International Campaign on Article 19 – Living in the Community*. <http://www.inclusion-international.org/home/inclusion-international-campaign-on-article-19/>.

People with disabilities are frequently segregated in institutions against their will where they are denied the opportunity to make decisions about their lives or participate in the community as equal citizens.

A large number of children and adults with disabilities are institutionalized globally. The United Nations (UN) estimates that up to eight million children live in institutions.<sup>72</sup> The UN figure is likely to be an underestimate, given that data collection and reporting in many countries is poor. For example, a European Commission-funded study of European Union member states and Turkey found that there are almost 1.2 million people with disabilities living in institutions in these countries alone.<sup>73</sup> The two largest groups who are institutionalized are people with mental health problems and people with intellectual disabilities.<sup>74</sup>

Institutionalization of persons with disabilities persists, and new institutions for persons with disabilities continue to be built. The European Union seeks to promote the social inclusion of people with disabilities. However, even in countries that are members of the European Union little has been done to address the institutionalization of people with disabilities and new institutions for people with disabilities continue to be built in some EU member states.

CRPD Article 19 obligates States parties to recognize the right of persons with disabilities to live in the community with choices equal to others and to ensure that they have the opportunity to choose their place of residence, and where and with whom they live. While CRPD Article 19 does not make specific reference to closing institutions, its provisions indicate that this is required. For example, the requirement that States parties ensure that persons with disabilities have access to community services that support their social inclusion and “prevent isolation or segregation from the community” is incompatible with persons continuing to be placed in institutions.<sup>75</sup>

### **Segregation in institutions isolates individuals from the community**

Segregation in long-stay institutions, such as psychiatric facilities, social care homes and orphanages, is the most significant human rights violation experienced by many children and adults with disabilities. The segregation of persons with disabilities in long-stay institutions is in itself a human rights abuse because it deprives them of their right to community living and to live independently. Furthermore, institutionalization reinforces the stigma and prejudice directed towards persons with disabilities and perpetuates the misconceptions that they are incapable or unworthy of participating in community life.<sup>76</sup>

In some countries, long-stay institutions are situated in remote rural areas. This means that residents rarely, if ever, receive visitors and have little or no communication with the outside world—in many cases for the rest of their lives. For example, a 2004 study of residential institutions in France, Hungary, Poland, and Romania found that “[c]ontact with family, friends and community is limited.”<sup>77</sup>

72 United Nations General Assembly, *Report of the independent expert for the United Nations study on violence against children*, A/61/299 (Aug. 29, 2006): 16. [http://www.unicef.org/violencestudy/reports/SG\\_violencestudy\\_en.pdf](http://www.unicef.org/violencestudy/reports/SG_violencestudy_en.pdf).

73 Mansell J et al, *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*, Volume 2: Main Report (Canterbury: Tizard Centre, University of Kent, 2007), (the DECLOC report). [http://www.kent.ac.uk/tizard/research/DECL\\_network/documents/DECLOC\\_Volume\\_1\\_Exec\\_Summary\\_final.pdf](http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_1_Exec_Summary_final.pdf).

74 Id.

75 Parker C, *A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities* (Open Society Foundations, Dec 2011). <http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf>; Hammarberg T, *The Right of People with Disabilities to Live Independently and be Included in the Community*, CommDH/Issue Paper, (Council of Europe, 2012). <https://wcd.coe.int/ViewDoc.jsp?id=1917847>.

76 United States Supreme Court, *Decision of Olmsted v. LC*, 527 US 581 (1999).

77 Freyhoff G et al, eds., *Included in Society - Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People* (European Commission, 2004). [http://www.community-living.info/contentpics/226/Included\\_in\\_Society.pdf](http://www.community-living.info/contentpics/226/Included_in_Society.pdf).

### **Segregation in institutions denies the right to make choices**

Institutional living denies persons with disabilities the right to choose where they live, how they live, and with whom they associate. Institutional life is inherently a strictly controlled living and does not provide opportunities for individuals to make choices.<sup>78</sup>

### **Segregation in institutions limits access to services within the community**

Conditions within many institutions are poor and residents are not provided with adequate support or services, including health and rehabilitation services. For example, the 2004 study mentioned above found that “[r]esidents often live lives characterized by hours of inactivity, boredom and isolation” and that “[s]taff numbers are frequently too low to provide habilitation and therapy.”<sup>79</sup>

### **Segregation in institutions limits participation in the community**

Institutionalized persons with disabilities face major challenges in exercising their fundamental rights to participate in the community. Particularly, institutionalized individuals are denied full and equal access to education and employment, two major methods of community participation. Institutionalized individuals are often denied educational opportunities, being either excluded from the education system or provided segregated or poor quality education. Likewise, persons with disabilities are often denied opportunities to work in the community. Some programs provide employment opportunities where persons with disabilities are grouped together and given menial tasks, disregarding the individual’s choices and right to participate in the community.

## **Isolation within the community and isolation by improper service delivery violate the right to community living**

Individuals living in a home or group home setting are also subject to violations of the right to live in the community. It is not the size of the residence that determines whether the right to live in community has been violated. Rather, the right to community is violated when an individual is denied the right to live independently, to exercise control over one’s life, and to participate in one’s community.

Violations of the right to community living occur when persons with disabilities living in a home or group home are isolated or segregated as a result of how services are delivered or by a lack of services available in the community. Violations occur:

*... when people with disabilities who need some form of support in their everyday lives are required to relinquish living in the community in order to receive that support; when support is provided in a way that takes away people’s control from their own lives; when support is altogether withheld, thus confining a person to the margins of the family or society; or when the burden is placed on people with disabilities to fit into public services and structures rather than these services and structures being designed to accommodate the diversity of the human condition.<sup>80</sup>*

<sup>78</sup> Hammarberg T, *The Right of People with Disabilities to Live Independently and be Included in the Community*, CommDH/Issue Paper, (Council of Europe, 2012). <https://wcd.coe.int/ViewDoc.jsp?id=1917847>.

<sup>79</sup> Freyhoff G et al, eds., *Included in Society - Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People* (European Commission, 2004). [http://www.community-living.info/contentpics/226/Included\\_in\\_Society.pdf](http://www.community-living.info/contentpics/226/Included_in_Society.pdf).

<sup>80</sup> Hammarberg T, *The Right of People with Disabilities to Live Independently and be Included in the Community*, CommDH/Issue Paper, (Council of Europe, 2012): 4. <https://wcd.coe.int/ViewDoc.jsp?id=1917847>.

This means that a person is denied their right to live in the community if he/she is prohibited from leaving the house, or faces barriers to accessing education or health services, or pursuing employment. Not only do structural barriers such as inaccessible places, technologies, or services cause isolation and segregation, but stigma and a lack of support within the community can also result in isolation of persons with disabilities from their communities.<sup>81</sup> These social, physical, and economic barriers or hindrances prevent full participation in the community, and constitute violations of CRPD Article 19.

## **Persons with disabilities living in institutions experience additional violations of their human rights, beyond the right to community living.**

Persons with disabilities living in institutions are at higher risk of torture and other cruel, inhuman or degrading treatment or punishment, in violation of CRPD Article 15. Reports have shown that residents of institutions are subjected to serious and sustained human rights violations, ranging from inadequate food, heating and clothing to barbaric treatment such as the unmodified (without anaesthesia or muscle relaxants) use of electro-convulsive therapy, the use of cage beds, sexual abuse, forced sterilisation and other forms of “treatment” without their consent.<sup>82</sup>

The United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (Special Rapporteur on Torture) explains the vulnerability of persons with disabilities in institutions to torture:

*Torture, as the most serious violation of the human right to personal integrity and dignity, presupposes a situation of powerlessness, whereby the victim is under the total control of another person. Persons with disabilities often find themselves in such situations, for instance when they are deprived of their liberty in prisons or other places, or when they are under the control of their caregivers or legal guardians. In a given context, the particular disability of an individual may render him or her more likely to be in a dependant situation and make him or her an easier target of abuse. However, it is often circumstances external to the individual that render them “powerless”, such as when one’s exercise of decision-making and legal capacity is taken away by discriminatory laws or practices and given to others.<sup>83</sup>*

Torture against persons with disabilities has been widely reported and documented within institutions. Persons with disabilities, when committed to a residential institution for long-term stay, are dependent upon the institution for their care, support and social needs. Persons with disabilities have been subjected to neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence inside institutions.<sup>84</sup> A lack of reasonable accommodation in detention facilities can increase the risk of neglect, violence, abuse, torture and ill-treatment.<sup>85</sup>

Torture in institutions must be addressed by prohibiting and terminating all institutionalized living. The Special Rapporteur on Torture, Juan Méndez, writes in his 2013 interim report that “The Committee on the Rights of Persons with Disabilities has been very explicit in calling for the prohibition of disability-based

<sup>81</sup> Id.

<sup>82</sup> Amnesty International, *Bulgaria: Far from the Eyes of Society: Systematic Discrimination against People with Mental Disabilities* (Oct. 2002). <http://www.amnesty.org/en/library/info/EUR15/005/2002>; Amnesty International and Mental Disability Advocacy Center, *Cage Beds: Inhuman and Degrading Treatment in Four Accession Countries* (2003). <http://www.mdac.info/en/resources/cage-beds-inhuman-and-degrading-treatment-or-punishment-four-eu-accession-countries>.

<sup>83</sup> United Nations General Assembly, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175* (July 28, 2008).

<sup>84</sup> United Nations General Assembly, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175* (July 28, 2008).

<sup>85</sup> Id.

detention, i.e. civil commitment and compulsory institutionalization or confinement based on disability. It establishes that community living, with support, is no longer a favourable policy development but an internationally recognized right.”<sup>86</sup>

## What is the human rights-based approach of community living?

### Right to community living

CRPD Article 19 establishes that people with disabilities have a right to live in the community and to participate in society as equal citizens. By ratifying the CRPD, States parties make a commitment to ensuring that persons with disabilities can live and participate fully in their communities. The right to community living requires the closing of institutions and prohibiting institutionalized living.<sup>87</sup> Therefore, governments must provide the support and structures that enable persons with disabilities to live and participate in the community. “This will encompass a range of services and supports such as housing, including supported housing, care in the family home, social work support, and supported employment, as well as access to mainstream services such as health care.”<sup>88</sup>

### CRPD Article 19: Living independently and being included in the community

States parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-house, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Community living is closely linked with other human rights including the right to liberty, non-discrimination, bodily integrity, privacy, and freedom from torture, violence, exploitation, and abuse. However, community living is more than the realization of these rights. “The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one’s life, wrought on people with disabilities because of their need for support against the background of an inaccessible society.”<sup>89</sup>

<sup>86</sup> Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb 2013). [http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53\\_English.pdf](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf).

<sup>87</sup> Parker C, *A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities* (Open Society Foundations, Dec 2011). <http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf>; Hammarberg T, *The Right of People with Disabilities to Live Independently and be Included in the Community*, CommDH/Issue Paper, (Council of Europe, 2012): 9. <https://wcd.coe.int/ViewDoc.jsp?id=1917847>.

<sup>88</sup> Parker C, *A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities* (Open Society Foundations, Dec 2011). <http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf>.

<sup>89</sup> Hammarberg T, *The Right of People with Disabilities to Live Independently and be Included in the Community*, CommDH/Issue Paper, (Council of Europe, 2012): 8. <https://wcd.coe.int/ViewDoc.jsp?id=1917847>.

Article 19 establishes that States parties can ensure full inclusion and participation in the community by (a) providing persons with disabilities to opportunity to choose where and with whom they live; (b) providing a range of support services; and (c) ensuring that all public services are provided to persons with disabilities on an equal basis. These three components of community living are each important to realizing community living:

1. **Choice.** Ensuring that persons with disabilities have the opportunity to choose where and with whom they live implicates the right to equal recognition before the law (Art 12 on legal capacity). Article 12 of the CRPD affirms the right of everyone to make their own decisions. Article 12(2) states that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an on equal basis with others in all aspects of life.” Therefore, current state laws on involuntary commitment and guardianship should be revisited in light of the rights articulated in Article 12 and Article 19.
2. **Individualized support services.** In order to ensure that persons with disabilities are enabled to live in the community, they must have access to a full range of services including housing and community support services, which includes personal assistance. Community support services could include a broad range of services including access to social workers, supported employment and access to health care. The CRPD establishes that access to all services necessary to “to prevent isolation or segregation from the community” is an essential component of the right to community living.

Many countries do not have the resources necessary to provide extensive services. However the CRPD provides in Article 4(2) that States parties are obligated to “take measures to the maximum of its available resources ... with a view to achieving progressively the full realization of these rights.” Therefore, States parties must continuously strive to implement the right to live in the community by taking steps over time and to the maximum of their resources. This extends to the State’s obligation to provide the resources and support services necessary to realize the right to community living for persons with disabilities.

3. **Inclusive community services.** Article 19 establishes that community services and facilities for the general population must be available on an equal basis to persons with disabilities and are responsive to their needs. This means that all public services and facilities must accessible to persons with disabilities, and reasonable accommodations should be made.

## Implementing the right to community living

Governments must make a commitment to community living in order to ensure the right of persons with disabilities to living in the community. The former Council of Europe’s Commissioner for Human Rights, Thomas Hammarberg recommends to “...set deinstitutionalisation as a goal and develop a transition plan for phasing out institutional options and replacing them with community-based services, with measurable targets, clear timetables and strategies to monitor progress.”<sup>90</sup>

When implementing community living policies and programs, governments should be guided in all decisions by the CRPD, especially the CRPD general principles. There is “less clarity with regard to the mechanisms that replace institutionalisation and would constitute a human rights-based response.”<sup>91</sup> Effective deinstitutionalisation requires an understanding that the right to community living is more than just access to the physical placement in the community; rather, living in the community is linked to issues of autonomy and choice.<sup>92</sup>

<sup>90</sup> Hammarberg T, *The Right of People with Disabilities to Live Independently and be Included in the Community*, CommDH/Issue Paper, (Council of Europe, 2012). <https://wcd.coe.int/ViewDoc.jsp?id=1917847>.

<sup>91</sup> Id.

<sup>92</sup> Id.



There are also budgetary considerations that must be accounted for in implementing the right to community living. “For living independently and being included in the community to become a reality, social policy reform is needed, which has budgetary implications, involves multiple stakeholders, and necessitates coordination across government ministries and local authorities.”<sup>93</sup>

To provide guidance on key areas of work that governments will need to take to comply with CRPD Article 19, the Open Society Public Health Program has developed a checklist.<sup>94</sup> The ten action points from this list are:

## **A Community for All: A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities**

1. Commit to transforming the system from institutional services to community-based services
2. Provide explicit recognition of the right to community living for all (the right of all persons with disabilities to live in the community, ‘with choices equal to others’)
3. Develop a national strategy for transforming the system from institutional placements to community-based services
4. Establish mechanisms to enable the participation of civil society, in particular, people with disabilities and their families
5. Develop links with experts (international and national)
6. Review legislation, policies and practices relevant to the implementation of Article 19
7. Review existing services for people with disabilities
8. Ensure transparency and accountability in the use of public funds
9. Establish mechanisms for data collection
10. Establish mechanisms for periodic review of the action plan and national strategy

Organizations are beginning to develop resources and tools to provide guidance on the process of deinstitutionalization and the transition to community living, and many of these are listed in the resources section of this chapter. For example, the European Expert Group on the Transition from Institutional to Community-based Care has published a resource that provides detailed guidance on transitioning from institutionalization to community living called “Common European Guidelines on the Transition from Institutional to Community Based Care”<sup>95</sup> as well as a toolkit on the use of European Union Funds.

<sup>93</sup> Id.

<sup>94</sup> Parker C, *A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities* (Open Society Foundations, Dec 2011). <http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf>.

<sup>95</sup> European Expert Group on the Transition from Institutional to Community-based Care, *Common European Guidelines on the Transition from Institutional to Community Based Care: Guidance on implementing and supporting a sustained transition from institutional care to family-based and community-based alternatives for children, persons with disabilities, persons with mental health problems and older persons in Europe* (Nov. 2012). <http://deinstitutionalisationguide.eu/wp-content/uploads/2012/12/2012-12-07-Guidelines-11-123-2012-FINAL-WEB-VERSION.pdf>. See also, European Expert Group on the Transition from Institutional to Community-based Care, *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care* (Nov. 2012). <http://deinstitutionalisationguide.eu/>.



## 2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO DISABILITY, HEALTH AND COMMUNITY LIVING?

### How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to persons with disabilities. The tables are organized as follows:

Human right or fundamental freedom	
<b>Examples of Human Rights Violations</b>	
<b>Human rights standards</b>	<p><b>UN treaty body interpretation</b></p> <p>This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.</p>
<b>Human rights standards</b>	<p><b>Case law</b></p> <p>This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.</p>
<p><b>Other interpretations:</b> This section references other relevant interpretations of the issue. It includes interpretations by:</p> <ul style="list-style-type: none"> <li>• UN Special Rapporteurs</li> <li>• UN working groups</li> <li>• International and regional organizations</li> <li>• International and regional declarations</li> </ul>	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on disability and human rights.

## Abbreviations

In the tables, we use the following abbreviations to refer to the thirteen treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights ( <b>UDHR</b> )	None
Convention on the Rights of Persons with Disabilities ( <b>CRPD</b> )	Committee on the Rights of Persons with Disabilities ( <b>CRPD</b> )
International Covenant on Civil and Political Rights ( <b>ICCPR</b> )	Human Rights Committee ( <b>HRC</b> )
International Covenant on Economic, Social, and Cultural Rights ( <b>ICESCR</b> )	Committee on Economic, Social and Cultural Rights ( <b>CESCR</b> )
Convention on the Elimination of All Forms of Discrimination Against Women ( <b>CEDAW</b> )	Committee on the Elimination of Discrimination Against Women ( <b>CEDAW Committee</b> )
International Convention on the Elimination of All Forms of Racial Discrimination ( <b>ICERD</b> )	Committee on the Elimination of Racial Discrimination ( <b>CERD</b> )
Convention on the Rights of the Child ( <b>CRC</b> )	Committee on the Rights of the Child ( <b>CRC Committee</b> )
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment ( <b>CAT</b> )	Committee against Torture ( <b>CAT</b> )
African Charter on Human and Peoples' Rights and Protocols ( <b>ACHPR</b> )	African Commission on Human and Peoples' Rights ( <b>ACHPR Commission</b> )
[European] Convention for the Protection of Human Rights and Fundamental Freedoms ( <b>ECHR</b> )	European Court of Human Rights ( <b>ECtHR</b> )
1996 Revised European Social Charter ( <b>ESC</b> )	European Committee of Social Rights ( <b>ECSR</b> )
American Convention on Human Rights ( <b>ACHR</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )
American Declaration of the Rights and Duties of Man ( <b>ADRDM</b> )	Inter-American Court of Human Rights ( <b>IACHR</b> )

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

**Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	UDHR	CRPD	ICCPR	ICESCR	CEDAW	ICERD	CRC
<b>Non-discrimination and Equality</b>	Art. 1, Art. 2	Art. 5	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
<b>Independent Living</b>		Art. 19					Art. 23(1,2)
<b>Supported Decision Making</b>		Art. 12					
<b>Equality before the Law</b>	Art. 6	Art. 5(1), Art. 12	Art. 16, Art. 26			Art. 5	
<b>Health</b>	Art. 25	Art. 25		Art. 12	Art. 12	Art. 5(e)(iv)	Art. 23(3, 4), Art. 24
<b>Informed Consent</b>		Art. 25(d)					
<b>Sexual and Reproductive Health</b>		Art. 25(a)			Art. 12(1), Art. 14(2)(b)		Art. 24(2)(f)
<b>Education</b>	Art. 26	Art. 24		Art. 13	Art. 10	Art. 5(e)(v)	Art. 23(3, 4), Art. 28, Art. 29
<b>Employment</b>	Art. 23	Art. 27		Art. 6, Art. 7	Art. 11	Art. 5(e)(i)	
<b>Life</b>	Art. 3	Art. 10	Art. 6(1)				Art. 6(1)
<b>Liberty and Security of Person</b>	Art. 3	Art. 14	Art. 9(1)				Art. 37(b)
<b>Exploitation, Violence and Abuse</b>		Art. 16					Art. 19, Art. 32(1), Art. 34, Art. 36
<b>Torture or Cruel, Inhuman or Degrading Treatment*</b>	Art. 5	Art. 15	Art. 7				Art. 37(a)

\*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

**Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms**

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Non-Discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
Independent Living			Art. 15		
Supported Decision Making					
Equality before the Law	Art. 3			Art. II, Art. XVII	Art. 3
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Informed Consent					
Sexual and Reproductive Health					
Education	Art. 17			Art. XII	
Employment	Art. 15		Art. 1	Art. XIV	
Life	Art. 4	Art. 2		Art. I	Art. 4
Liberty and Security of Person	Art. 6	Art. 5(1)		Art. I	Art. 7(1)
Exploitation, Violence and Abuse	Art. 5				
Torture or Cruel, In-human or Degrading Treatment	Art. 5	Art. 3			Art. 5(2)

**Table I: Disability and non-discrimination**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Persons with disabilities are disproportionately underrepresented in the labor market.</li> <li>• Persons with disabilities are not provided an accommodation to ensure access to health care services or places of work.</li> <li>• Children with disabilities are discriminated against in the classroom because teachers misunderstand the disability or consider the child 'handicapped'.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 5 (1)</b> States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.</p> <p><b>(2)</b> States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.</p> <p><b>(3)</b> In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.</p> <p><b>(4)</b> Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.</p>	<p><b>CRPD:</b> recommending that <b>Argentina</b> “incorporate the concept of reasonable accommodation into its anti-discrimination legislation and to ensure that the relevant laws and regulations define the denial of reasonable accommodation as a form of discrimination on grounds of disability. The Committee recommends that the State party take steps to simplify existing judicial and administrative remedies in order to enable persons with disabilities to report acts of discrimination to which they have been subjected. The Committee also recommends that the State party devote special attention to the development of policies and programmes for persons with disabilities who belong to indigenous peoples and for deaf-blind persons with a view to putting an end to the many forms of discrimination to which these persons may be subjected.” CRPD/C/ARG/CO/1 (CRPD, 2012).</p> <p><b>CRPD:</b> reiterating to <b>Spain</b> that the denial of reasonable accommodation constitutes discrimination and that the duty to provide reasonable accommodation is immediately applicable and not subject to progressive realization. CRPD/C/ESP/CO/1 (2011).</p> <p><b>CRPD:</b> “[t]he Committee urges <b>Spain</b> to expand the protection of discrimination on the grounds of disability to explicitly cover multiple disability, perceived disability and association with a person with a disability, and to ensure the protection from denial of reasonable accommodation, as a form of discrimination, regardless of the level of disability. Moreover, guidance, awareness-raising and training should be given to ensure a better comprehension by all stakeholders, including persons with disabilities, of the concept of reasonable accommodation and prevention of discrimination. CRPD/C/ESP/CO/1 (2011).</p> <p><b>CRPD:</b> calling upon <b>Hungary</b> to adopt effective and specific measures to ensure equality and prevent multiple forms of discrimination of women and girls with disabilities in its policies, and to mainstream a gender perspective in its disability-related legislation and policies. CRPD/C/HUN/CO/1 (2012).</p> <p><b>CRPD:</b> calling upon <b>Hungary, Spain, Tunisia and China</b> to take steps to ensure that its legislation explicitly prescribes that failure to provide reasonable accommodation constitutes a prohibited act of discrimination. CRPD/C/HUN/CO/1 (2012), CRPD/C/ESP/CO/1 (2011), CRPD/C/TUN/CO/1 (2011), CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> urging <b>China</b> to take measures to fight the widespread stigma in relation to boys and girls with disabilities and revise their strict family planning policy so as to combat the root causes for the abandonment of boys and girls with disabilities. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>Peru</b> place emphasis on the development of policies and programmes on indigenous and minority persons with disabilities—in particular women and children with disabilities that live in rural areas, as well as persons of African descent—in order to address the multiple forms of discrimination that these persons may suffer. CRPD/C/PER/CO/1 (2012).</p>

**Table I (cont.)**

Human Rights Standards	Treaty Body Interpretation
	<p><b>CRPD:</b> urging that <b>Peru</b> accelerate its efforts to eradicate and prevent discrimination against women and girls with disabilities by incorporating gender and disability perspectives in all programmes, as well as by ensuring their full and equal participation in decision-making. The Committee also urged Peru to amend its legislative framework to provide special protection to women and girls with disabilities, as well as to adopt effective measures to prevent and redress violence against women and girls with disabilities. CRPD/C/PER/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>Tunisia</b> act with urgency to include an explicit prohibition of disability-based discrimination in an anti-discrimination law, as well as ensure that disability-based discrimination is prohibited in all laws, particularly those governing elections, labor, education, and health, among others. CRPD/C/TUN/CO/1(2011).</p>
<p><b>CRC 3 (1)</b> States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community ...</p>	<p><b>CRC Committee:</b> recommending that <b>Azerbaijan</b> “undertake awareness-raising campaigns on eliminating discrimination against children with disabilities, and consider enacting legislation explicitly prohibiting such discrimination.” CRC/C/AZE/CO/3-4 (CRC, 2012).</p> <p><b>CRC Committee:</b> recommending that <b>Australia</b> and <b>Azerbaijan</b> “establish a clear legislative definition of disability, including for learning, cognitive and mental disabilities, with the aim of accurately identifying children with disabilities to effectively address their needs in a non-discriminatory manner.” CRC/C/AUS/CO/4 (CRC, 2012); CRC/C/AZE/CO/3-4 (CRC, 2012).</p> <p><b>CRC Committee:</b> recommending that <b>Andorra</b> “Increase budget allocations to provide children with disabilities with equal access to adequate social and health services, including psychological support , counselling services, parental guidance for families of children with disabilities, and tailored services for children with learning difficulties and behavioural disorders, and raise awareness about all services available.” CRC/C/AND/CO/2 (CRC, 2012).</p> <p><b>CRC Committee:</b> recommending that <b>Namibia</b> “Ensure that all legislation on children, including the proposed Child Care and Protection Bill, include a specific prohibition of discrimination on the ground of disability, and develop holistic and coordinated programmes across ministries on the rights of children with disabilities.” CRC/C/NAM/CO/2-3 (CRC, 2012).</p>

**Table 2: Disability and the right to live independently and be included in the community (community living)**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Persons with disabilities who are institutionalized.</li> <li>• Dedication of resources to the reconstruction of large residential institutions.</li> <li>• Lack of resources and services to help persons with disabilities live within their communities.</li> <li>• A child is placed in an institution because she is diagnosed with Down Syndrome and her parents are told that there is no support available to help them raise her at home.</li> <li>• A young man with intellectual disabilities is admitted to a social care home far from his home because his mother has become ill and can no longer look after him without some help.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 19</b> States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:</p> <p><b>(a)</b> Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;</p> <p><b>(b)</b> Persons with disabilities have access to a range of in-, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;</p> <p><b>(c)</b> Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.</p>	<p><b>CRPD:</b> recommending that <b>Spain</b> ensure an adequate level of funding is made available to effectively enable persons with disabilities to: enjoy the freedom to choose their residence on an equal basis with others; access a full range of in-home, residential and other community services for daily life, including personal assistance; and enjoy reasonable accommodation so as to better integrate into their communities. CRPD/C/ESP/CO/1 (2011).</p> <p><b>CRPD:</b> encouraging <b>Spain</b> to expand resources for personal assistants to all persons with disabilities in accordance with their requirements. CRPD/C/ESP/CO/1 (2011).</p> <p><b>CRPD:</b> recommending that <b>Argentina</b> “implement the deinstitutionalization strategies that it has adopted in an effective manner and to develop and implement mental health plans based on the human rights model of disability, along with effective measures to promote the deinstitutionalization of persons with disabilities.” CRPD/C/ARG/CO/1 (CRPD, 2012)</p> <p><b>CRPD:</b> calling upon <b>Hungary</b> “to ensure that an adequate level of funding is made available to effectively enable persons with disabilities to: enjoy the freedom to choose their residence on an equal basis with others; access a full range of in-home, residential and other community services for daily life, including personal assistance; and enjoy reasonable accommodation with a view to supporting their inclusion in their local communities.” CRPD/C/HUN/CO/1 (2012).</p> <p><b>CRPD:</b> calling upon <b>Hungary</b> to take appropriate measures to enable men and women with disabilities who are of marriageable age to marry and found a family, as well as to provide adequate support services to men and women, boys and girls with disabilities to enable them to live with their families, with a view to prevent and reduce the risk of placement in an institution. CRPD/C/HUN/CO/1 (2012).</p> <p><b>CRPD:</b> calling upon <b>Hungary</b> to undertake greater efforts to make available the necessary professional and financial resources, especially at the local level, to promote and expand community-based rehabilitation and other services in their respective local communities to children with disabilities and their families, in order to enable children with disabilities to live with their families, as recommended by the Committee on the Rights of the Child (CRC/C/HUN/CO/2). CRPD/C/HUN/CO/1 (2012).</p>



**Table 2 (cont.)**

Human Rights Standards	Treaty Body Interpretation
	<p><b>CRPD:</b> recommending that <b>China</b> take immediate steps to phase out and eliminate institutional-based care for people with disabilities. Further, the Committee recommends China to consult with organisations of persons with disabilities on developing support services for persons with disabilities to live independently in accordance with their own choice. Support services should also be provided to persons with a high level of support needs. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> develop a wide range of community-based services and supports that respond to needs expressed by persons with disabilities, and respect the person’s autonomy, choices, dignity and privacy, including peer support and other alternatives to the medical model of mental health. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> urging <b>Peru</b> to initiate comprehensive programmes to enable persons with disabilities to access a whole range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community, especially in rural areas. CRPD/C/PER/CO/1 (2012).</p>
<p><b>CRC 23 (1)</b> States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.</p>	<p><b>CRC General Comment No. 7:</b> explaining that “[e]arly childhood is the period during which disabilities are usually identified and the impact on children’s wellbeing and development recognized. Young children should never be institutionalized solely on the grounds of disability. It is a priority to ensure that they have equal opportunities to participate fully in education and community life, including by the removal of barriers that impede the realization of their rights. Young disabled children are entitled to appropriate specialist assistance, including support for their parents (or other caregivers). Disabled children should at all times be treated with dignity and in ways that encourage their self-reliance.” CRC/C/GC/7/Rev.1 (2006), para. 36(d).</p> <p><b>CRC Committee:</b> recommending that <b>Australia</b> “Take measures to de-institutionalize children with disabilities and further strengthen support to families to enable them to live with their parents.” CRC/C/AUT/CO/3-4 (CRC, 2012).</p> <p><b>CRC Committee:</b> recommending that <b>Egypt</b> “[s]trengthen the availability and accessibility of community-based educational and health services for children with disabilities, in particular by strengthening inclusive education which promotes the child’s self-reliance and active participation in the community in line with article 23, paragraph 1 of the Convention.” CRC/C/EGY/CO/3-4 (CRC, 2011).</p> <p><b>CRC Committee:</b> recommending that the <b>Czech Republic</b> implement of measures to provide alternatives to the institutionalization of disabled and for the strengthening of community-based programmes to enable them to stay at home with their families in. CRC/C/15/ADD.201 (CRC, 2003), para. 49.</p> <p><b>CRC Committee:</b> recommending that <b>Hungary</b> implement community-based rehabilitation programmes, including parent support groups, to avoid the marginalization and exclusion of disabled children and children with disabled parents. CRC/C/HUN/CO/2 (CRC, 2006), para. 40.</p>

## Table 2 (cont.)

### Other Interpretations

**The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** 1993: “Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of health, employment and social services.”

**Council of Europe Commissioner for Human Rights:** “The right to live in the community applies to all people with disabilities. No matter how intensive the support needs, everyone, without exception, has the right and deserves to be included and provided with opportunities to participate in community life. Time and again it has been demonstrated that people who were deemed too ‘disabled’ to benefit from community inclusion thrive in an environment where they are valued, where they partake in the everyday life of their surrounding community, where their autonomy is nurtured and they are given choices.” (CommDH/IssuePaper(2012)3).

**Council of Europe,** Recommendation (2006) 5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015: “People with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community. Enhancing community living . . . requires strategic policies which support the move from institutional care to community-based settings . . . .”

**The Parliamentary Assembly of the Council of Europe,** Report of the Social, Health and Family Affairs Committee: “The practice of placing children and adults with disabilities into institutions undermines their inclusion as they are kept segregated from the rest of society and suffer serious damage to their healthy development and obstruction of the exercise of other rights. Deinstitutionalisation is a prerequisite to enabling people with disabilities to become as independent as possible and take their place as full citizens with the opportunity to access education and employment, and a whole range of other services.” Doc 11694 (August 8, 2008).

**Table 3: Disability and the right to supported decision-making**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>An individual is denied the right to make decisions about their life because the court has declared them legally incapacitated and appointed a guardian.</li> <li>An individual is denied the opportunity to decide where he/she lives and with whom.</li> <li>An individual is denied the right to vote because the court has declared them legally incapacitated.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 12 (2)</b> States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.</p> <p><b>(3)</b> States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.</p> <p><b>(4)</b> States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.</p>	<p><b>CRPD:</b> recommending that <b>Argentina</b> “launch an immediate review of all current legislation that is based on a substitute decision-making model that deprives persons with disabilities of their legal capacity. At the same time, the Committee urges the State party to take steps to adopt laws and policies that replace the substitute decision-making system with a supported decision-making model that upholds the autonomy, wishes and preferences of the persons concerned. In addition, the Committee recommends that training workshops on the human rights model of disability be organized for judges to encourage them to adopt the supported decision-making system instead of granting guardianships or trusteeships.” CRPD/C/ARG/CO/1 (CRPD, 2012)</p> <p><b>CRPD:</b> recommending that <b>Spain</b> and <b>Tunisia</b> review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences. It further recommends that training be provided on this issue for all relevant public officials and other stakeholders. CRPD/C/ESP/CO/1 (2011), CRPD/C/TUN/CO/1(2011).</p> <p><b>CRPD:</b> recommending that <b>Hungary</b> use effectively the current review process of its Civil Code and related laws to take immediate steps to derogate guardianship in order to move from substitute decision-making to supported decision-making, which respects the person's autonomy, will and preferences and is in full conformity with article 12 of the Convention, including with respect to the individual's right, on their own, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry, to work, and to choose their place of residence. CRPD/C/HUN/CO/1 (2012).</p> <p><b>CRPD:</b> urging <b>China</b> to “adopt measures to repeal the laws, policies and practices which permit guardianship and trusteeship for adults and take legislative action to replace regimes of substituted decision-making by supported decision making, which respects the person's autonomy, will and preferences, in the exercise of one's legal capacity in accordance with Article 12 of the CRPD. In addition, the Committee recommended that China, in consultation with DPOs, prepare a blueprint for a system of supported decision-making, and legislate and implement it which includes:</p> <ul style="list-style-type: none"> <li>Recognition of all persons' legal capacity and right to exercise it.</li> <li>Accommodations and access to support where necessary to exercise legal capacity.</li> <li>Regulations to ensure that support respects the person's autonomy, will and preferences and establishment of feedback mechanisms to ensure that support is meeting the person's needs.</li> <li>Arrangements for the promotion and establishment of supported decision-making.” CRPD/C/CHN/CO/1 (2012).</li> </ul> <p><b>CRPD:</b> urging <b>Peru</b> to abolish the practice of judicial interdiction and review the laws allowing for guardianship and trusteeship to ensure their full conformity with article 12 of the Convention and to take action to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will, and preferences. CRPD/C/PER/CO/1 (2012).</p>

**Table 4: Disability and equality before the law**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Persons with disabilities are not given identity cards.</li> <li>• Persons with disabilities who are declared incompetent by a court are consequently also denied civil rights such as the right to vote.</li> <li>• No legal remedies and safeguards against guardianship, such as independent review and right to appeal.</li> <li>• Persons with disabilities are denied the ability to exercise the right to marry.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 12 (1)</b> States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.</p> <p><b>(2)</b> States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.</p> <p><b>(3)</b> States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. ...</p>	<p><b>CRPD:</b> noting that in <b>Peru</b> it is reported “that a number of persons with disabilities, especially those living in rural areas and in long-term institutional settings, do not have identity cards and, sometimes, have no name” and urging <b>Peru</b> to promptly initiate programmes in order to provide identity documents to persons with disabilities, including in rural areas and in long-term institutional settings, and to collect complete and accurate data on people with disabilities in institutions who are currently undocumented and/or do not enjoy their right to a name. CRPD/C/PER/CO/1 (2012).</p> <p><b>CRPD:</b> urging <b>Peru</b> to amend the Civil Code in order to adequately guarantee the exercise of civil rights, particularly with regards to the right to marry to all persons with disabilities. CRPD/C/PER/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> revise their laws to ensure that all persons with disabilities have the right to vote. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>Peru:</b></p> <ol style="list-style-type: none"> <li>“Restore voting rights to all people with disabilities who are excluded from the national voter registry, including people with disabilities subject to judicial interdiction.</li> <li>Reach out to vulnerable individuals and protect people with disabilities from such violations in the future, including through relevant training.</li> <li>Guarantee the right to vote of people with disabilities in institutions, by ensuring that they are physically permitted to go to assigned polling stations and have the support required to do so, or to permit alternative options.” CRPD/C/PER/CO/1 (2012).</li> </ol>

**Table 5: Disability and the right to the highest attainable standard of health**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A person with a disability is denied care at a local health center because the physician does not know how to care for them.</li> <li>• A person with limited mobility cannot access a health care facility.</li> <li>• Rural citizens with disabilities cannot access health facilities because they are too far.</li> <li>• A person with a disability does not have the ability to pay for needed health care services.</li> <li>• Specialized health services for children with disabilities are not readily available leading to late diagnosis and/or improper treatment.</li> <li>• Lack of early detection programmes of disabilities for children.</li> <li>• There are no rehabilitation services offered to individuals with disabilities in a certain city.</li> <li>• A woman with a schizophrenia diagnosis is told by nursing staff that her abdominal pain is 'all in your head'. She is later diagnosed with ovarian cancer.</li> <li>• Women with disabilities are denied reproductive health services.</li> </ul>

While States parties have an obligation to move as expeditiously as possible towards the full realization of the right to health, States are immediately obligated to ensure non-discrimination in access to health care. Therefore, discrimination on the basis of disability is prohibited regardless of a State's resources.

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 25</b> States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: . . .</p> <p><b>(d)</b> Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;</p>	<p><b>CRPD:</b> recommending that <b>China</b> adopt measures to ensure that all health care and services provided to persons with disabilities, including all mental health care and services, be based on the free and informed consent of the individual concerned, and that laws permitting involuntary treatment and confinement, including upon the authorisation of third party decision-makers such as family members or guardians, be repealed and that <b>China</b> develop a wide range of community-based services and supports that respond to needs expressed by persons with disabilities, and respect the person's autonomy, choices, dignity and privacy, including peer support and other alternatives to the medical model of mental health. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> "allocate more human and financial resources to the public medical services and arrange the cooperation of the insurance companies." CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> urging <b>Peru</b> to "elaborate comprehensive health programmes in order to ensure that persons with disabilities are specifically targeted and have access to rehabilitation and health services in general" and to:</p> <ul style="list-style-type: none"> <li>• "Review its legal framework in order to ensure that insurance companies and other private parties do not discriminate against persons with disabilities;</li> <li>• Apply budgetary resources and create skills among health personnel, in order to effectively comply with the right to health care of persons with disabilities, ensuring that hospitals and health centres are accessible to persons with disabilities;</li> </ul> <p>Provide services of early identification of disabilities, in particular deafness, designed to minimize and prevent further disabilities, including among children." CRPD/C/PER/CO/1 (2012).</p>

**Table 5 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 12(1)</b> The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p><b>CESCR, General Comment 14</b>, para 19: “States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds.”</p> <p><b>CESCR, General Comment No. 5</b>, para. 34: “States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society. The right to physical and mental health also implies the right to have access to, and to benefit from, those medical and social services—including orthopaedic devices—which enable persons with disabilities to become independent, prevent further disabilities and support their social integration. Similarly, such persons should be provided with rehabilitation services which would enable them to reach and sustain their optimum level of independence and functioning.’ All such services should be provided in such a way that the persons concerned are able to maintain full respect for their rights and dignity.”</p>
<p><b>CRC 3(3)</b> States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.</p> <p><b>CRC 24(1)</b> States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p><b>CRC Committee:</b> recommending that <b>Egypt</b> strengthen the availability and accessibility of community-based educational and health services for children with disabilities; ensure that all children with disabilities regardless of their status, enjoy access to rehabilitation services and increase the coverage of community-based rehabilitation facilities across its territory; and review the current health insurance system in order to cover all children and to lower the cost of health services for the most disadvantaged families.” CRC/C/EGY/CO/3-4 (CRC, 2011).</p> <p><b>CRC Committee:</b> recommending that <b>Bolivia</b> establish systems of early identification and early intervention as part of their health services; and undertake greater efforts to make available the necessary professional (i.e. disability specialists) and financial resources, especially at the local level and to promote and expand community-based rehabilitation programmes, including parent support groups to ensure that all children with disabilities receive adequate services. CRC/C/BOL/CO/4 (CRC, 2009).</p> <p><b>CRC Committee:</b> recommending that <b>Malaysia</b> provide children with disabilities with equal access to adequate social and health services, including psychological and counselling services, and tailored services for children with learning difficulties and behavioural disorders, and raise awareness about all services available. CRC/C/MYS/CO/1 (CRC, 2007).</p> <p><b>CRC Committee:</b> recommending that <b>Finland</b> “Establish a holistic legal and policy framework to guarantee the equal right of children with disabilities to access good-quality health -care services, public buildings and transportation.” CRC/C/FIN/CO/4 (CRC, 2011).</p>

**Table 5 (cont.)**

Human Rights Standards	Case Law
<p><b>ACHPR 16(1)</b> Every individual shall have the right to enjoy the best attainable state of physical and mental health.</p> <p><b>ACHPR 16(2)</b> States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.</p>	<p><b>ACHPR:</b> In a case against <b>The Gambia</b>, the Court held that the Lunatics Detention Act (LDA), the principle instrument governing mental health, is outdated for many reasons: overcrowding, no requirement for consent to treatment, no independent examination for the living conditions in units, and patients cannot vote. The Court ordered Gambia to repeal the law and develop new legislation for mental health in conformance with international norms and standards. 241/01 Purohit and Moore / Gambia (The) (May 2003).</p>

**Other Interpretations**

**The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** 1993: “Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of health, employment and social services.”

**The Declaration on the Promotion of Patients’ Rights in Europe**, promulgated by a WHO European Consultation: “Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider.” World Health Organization, *A Declaration on the Promotion of Patients’ Rights in Europe* art. 5.3 (Copenhagen: WHO, 1994). Available at [http://www.who.int/genomics/public/eu\\_declaration1994.pdf](http://www.who.int/genomics/public/eu_declaration1994.pdf).

**Charter of Fundamental Rights of the European Union**, art. 35. Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.



**Table 6: Disability and the right to informed consent**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• People with disabilities are deprived of their right to provide or deny consent to treatment.</li> <li>• Women with disabilities are subject to sterilization without their full and informed consent.</li> <li>• Persons with disabilities are subjected to medical experimentation without their consent.</li> <li>• Persons with disabilities are subjected to forced medications.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 25</b> States shall (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent ...</p>	<p><b>CRPD:</b> urging <b>Hungary</b> to amend Act CLIV on Healthcare and abolish its provisions that provide a legal framework for subjecting persons with disabilities with restricted legal capacity to medical experimentation without their free and informed consent. The Committee recommended to Hungary that it implement the recommendation made by the Human Rights Committee in 2010 (CCPR/C/HUN/CO/5) to “establish an independent medical examination body mandated to examine alleged victims of torture and guarantee respect for human dignity during the conduct of medical examinations.” CRPD/C/HUN/CO/1 (2012).</p> <p><b>CRPD:</b> expressing concern to <b>Tunisia</b> about the lack of clarity concerning the scope of legislation to protect persons with disabilities from being subjected to treatment without their free and informed consent, including forced treatment in mental health services; and recommending that Tunisia incorporate into the law the abolition of surgery and treatment without the full and informed consent of the patient, and ensure that national law especially respects women’s rights under article 23 and 25 of the Convention. CRPD/C/TUN/CO/1 (2011).</p> <p><b>CRPD:</b> urging that <b>China</b> cease its policy of subjecting persons with actual or perceived impairments to “correctional therapy” and abstains from involuntarily committing them to institutions. It furthered urged China to abolish laws that allow for medical experimentation on persons with disabilities without their free and informed consent. CRPD/C/CHN/CO/1 (2012)</p> <p><b>CRPD:</b> recommending to <b>China</b> that rights based approach to rehabilitation and habilitation be put in place and ensure that such programmes promote the informed consent of individuals with disabilities and respects their autonomy, integrity, will and preference. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> adopt measures to ensure that all health care and services provided to persons with disabilities, including all mental health care and services, is based on the free and informed consent of the individual concerned, and that laws permitting involuntary treatment and confinement, including upon the authorisation of third party decision-makers such as family members or guardians, are repealed. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> noting that in <b>Argentina</b>, there is a “lack of clear-cut mechanisms for ensuring that persons with disabilities give their free and informed consent. for any type of medical treatment before it is administered” and recommending that <b>Argentina</b> “adopt protocols for ensuring that all persons with disabilities give their free and informed consent for any type of medical treatment before it is administered.” CRPD/C/ARG/CO/1 (CRPD, 2012).</p> <p><b>CRPD:</b> recommending that <b>Spain</b> “ensure that the informed consent of all persons with disabilities is secured on all matters relating to medical treatment, especially the withdrawal of treatment, nutrition or other life support.” CRPD/C/ESP/CO/1 (CRPD, 2011).</p>

**Table 7: Disability and the right to sexual and reproductive health**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>• Women with disabilities are subject to compulsory abortions.</li> <li>• Women with disabilities are subject to involuntary sterilization.</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 25</b> States shall (a) provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.</p> <p><b>CRPD 17</b> Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.</p> <p><b>CRPD 23 (1)</b> States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:</p> <p>(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.</p>	<p><b>CRPD:</b> recommending that <b>Spain</b> abolish the administration of medical treatment, in particular sterilization, without the full and informed consent of the patient; and ensure that national law especially respects women’s rights under articles 23 and 25 of the Convention. CRPD/C/ESP/CO/1 (2011).</p> <p><b>CRPD:</b> calling upon <b>Peru</b> to abolish administrative directives on forced sterilization of persons with disabilities. CRPD/C/PER/CO/1(2012).</p> <p><b>CRPD:</b> calling upon <b>China</b> to prohibit compulsory sterilization and forced abortion on women with disabilities. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> regretting that, in <b>Argentina</b>, “in cases where a woman with disabilities is under guardianship, her legal representative may give consent for a legal abortion on her behalf. It is likewise concerned that persons with disabilities are being sterilized without their free and informed consent.” CRPD/C/ARG/CO/1 (CRPD, 2012).</p> <p><b>CRPD:</b> recommending that <b>Argentina</b> “amend article 86 of its Criminal Code and article 3 of Contraceptive Surgery Act No. 26.130 so that they will be in accordance with the Convention and take steps to provide the necessary support to women under guardianship or trusteeship to ensure that the women themselves are the ones who give their informed consent for a legal abortion or for sterilization.” CRPD/C/ARG/CO/1 (CRPD, 2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> ensure that “sex education be taught to children and adolescents with intellectual disabilities.” CRPD/C/CHN/CO/1 (2012).</p>
	<p><b>CESCR</b> General Comment 5, para. 31: explaining that “[w]omen with disabilities have the right to protection and support in relation to motherhood and pregnancy... The needs and desires in question should be recognized and addressed in both the recreational and procreational contexts.”</p>
<p><b>CEDAW 12(1)</b> States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health services, including those related to family planning.</p>	<p><b>CEDAW Committee:</b> recommending that <b>Australia</b> “enact national legislation prohibiting, except where there is a serious threat to life or health, the use of sterilization of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent.” CEDAW/C/AUL/CO/7 (2010).</p> <p><b>CEDAW Committee:</b> noting that the <b>Czech Republic</b> “has not implemented the 2005 recommendations of the ombudsman, endorsed by the committee in 2006, to adopt without delay legislative changes with regard to sterilization, including a clear definition of free, prior and informed consent in cases of sterilization and to financially compensate the victims of coercive or non-consensual sterilizations performed on, in particular, Roma women and women with mental disabilities.” CEDAW/C/CZE/CO/5 (CEDAW, 2010).</p>

**Table 8: Disability and the right to education**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Parents of a child with intellectual disabilities are told that their daughter cannot go to school because she is ‘uneducable.’</li> <li>• No education is provided to children in an institution.</li> <li>• A person with a disability is denied vocational training on the basis of their disability.</li> <li>• Parents of a child with a disability are not provided adequate resources to assist them in sending their child to school.</li> <li>• A child with a disability does not attend the local school because of the lack of transportation.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 24(1)</b> States Parties recognize the right of persons with disabilities to education . . .</p> <p><b>CRPD 24(2)</b> In realizing this right, States Parties shall ensure that: (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory education, or from secondary education, on the basis of disability.</p>	<p><b>CRPD:</b> recommending that <b>Argentina</b> “develop a comprehensive State education policy that guarantees the right to inclusive education and allocates sufficient budgetary resources to ensure progress towards the establishment of an education system that includes students with disabilities. The Committee also urges the State party to intensify its efforts to ensure that all children with disabilities receive a full compulsory education as established by the State party, while devoting particular attention to indigenous peoples and other rural communities. It likewise urges the State party to take the necessary steps to ensure that pupils with disabilities who attend special schools are enrolled in inclusive schools and to offer reasonable adjustments for students with disabilities within the general education system.” CRPD/C/ARG/CO/1 (CRPD, 2012).</p> <p><b>CRPD:</b> recommending that <b>Spain</b></p> <ol style="list-style-type: none"> <li>“Increase its efforts to provide reasonable accommodation in education, by: allocating sufficient financial and human resources to implement the right to inclusive education; paying particular attention to assessing the availability of teachers with specialist qualifications; and ensuring that educational departments of local governments understand their obligations under the Convention and act in conformity with its provisions;</li> <li>Ensure that the decisions to place children with a disability in a special school or in special classes, or to offer them solely a reduced - standard curriculum, are taken in consultation with the parents;</li> <li>Ensure that the parents of children with disabilities are not obliged to pay for the education or for the measures of reasonable accommodation in mainstream schools;</li> <li>Ensure that decisions on placing children in segregated settings can be appealed swiftly and effectively.” CRPD/C/ESP/CO/1 (CRPD, 2011).</li> </ol> <p><b>CRPD:</b> recommending that <b>China</b> “reallocate resources from the special education system to promote the inclusive education in mainstream schools, so as to ensure that more children with disabilities can attend mainstream education.” CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>Peru</b> “allocate sufficient budget resources to achieve advances in the progress for an inclusive education system for children and adolescents with disabilities, and take appropriate measures to identify and reduce illiteracy among children with disabilities, especially indigenous and Afro-Peruvian children.” CRPD/C/PER/CO/1 (2012).</p> <p><b>CRPD:</b> noting that in <b>Tunisia</b> “the inclusion strategy is not equally implemented in schools; rules relating to the number of children in mainstream schools and to the management of inclusive classes are commonly breached; and schools are not equitably distributed between regions of the same governorate.” CRPD/C/TUN/CO/1 (CRPD, 2011).</p>

**Table 8 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>CRC 28(1)</b> States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:</p> <p>(a) Make primary education compulsory and available free to all;</p> <p>(c) Make higher education accessible to all on the on the basis of capacity by every appropriate means;</p> <p>(e) Take measures to encourage regular attendance at schools and the reduction of drop-out rates.</p>	<p><b>CRC Committee:</b> recommending that <b>Australia</b> “Give priority to inclusive education of children with disabilities and ensure that the best interests of each child are a primary consideration in decisions concerning his/her school enrolment.” CRC/C/AUT/CO/3-4 (CRC, 2012).</p> <p><b>CRC Committee:</b> recommending that <b>Bosnia and Herzegovina</b> “Ensure that children with disabilities enjoy their right to education, and provide for their inclusion in the mainstream education system to the greatest extent possible, including by developing a disability education action plan to specifically identify current inadequacies in resources, and to establish clear objectives with concrete timelines for the implementation of measures to address the educational needs of children with disabilities.” CRC/C/BIH/CO/2-4 (CRC, 2012).</p> <p><b>CRC Committee:</b> recommending that <b>Namibia</b> “Ensure that children with disabilities are able to exercise their right to education, and provide for their inclusion in the mainstream education system to the greatest extent possible, including by providing teachers with special training, by increasing facilities for children with disabilities and by making schools more accessible.” CRC/C/NAM/CO/2-3 (CRC, 2012).</p> <p><b>CRC Committee:</b> stating to <b>Italy</b> that “[w]hile welcoming efforts to integrate children with disabilities in the school system, the Committee is concerned that disability is still conceptualized as a “handicap” rather than approached with the aim of ensuring the social inclusion of children with disabilities, and that there are regional disparities in the provision of specialist teachers in schools” and recommending that <b>Italy</b> “provide sufficient numbers of specialist teachers to all schools so that all children with disabilities can enjoy access to high - quality inclusive education.” CRC/C/ITA/CO/3-4 (CRC, 2011).</p> <p><b>CRC Committee:</b> recommending that <b>Cyprus</b> “establish a clear legislative definition of inclusive education. It further recommends that the State party adopt measures, including reasonable accommodation in all schools, to ensure that children with disabilities are able to exercise their right to education, and provide for their inclusion in the mainstream education system.” CRC/C/CYP/CO/3-4 (CRC, 2012).</p> <p><b>CRC Committee:</b> raising concerns to <b>Bulgaria</b> about the inadequate education for children in “social care institutions” and considers these children need to be provided with mainstream education. CRC/C/BGR/CO/2, 2008.</p> <p><b>CRC Committee:</b> concerned about the limited inclusion of children with disabilities in the educational system in <b>Kazakhstan</b> and <b>Ukraine</b>. CRC/C/15/ADD.213 (CRC, 2003), para. 54; CRC/C/15/ADD.191 (CRC, 2002), para. 53.</p> <p><b>CRC Committee:</b> noting the limited number of trained teachers to work with children with disabilities, insufficient efforts made to facilitate the children’s inclusion into the educational system, and inadequate resources allocated to special education in <b>India</b>, <b>Rwanda</b>, and <b>Zambia</b>. CRC/C/15/ADD.228 (CRC, 2004), para. 56; CRC/C/15/ADD.234 (CRC, 2004), para. 46; CRC/C/15/ADD.206 (CRC, 2003), para. 52.</p> <p><b>CRC Committee:</b> recommending that <b>Kyrgyzstan</b> integrate children with disabilities into the regular educational system and for increased resources for special education. CRC/C/15/Add.244 (CRC, 2004), para. 48.</p>

**Table 8 (cont.)**

Human Rights Standards	Case Law
<p><b>ESC 15</b> ... the Parties undertake in particular (1) to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;</p> <p><b>ESC 17(1)</b> With a view to ensuring the effective exercise of the right of children and young persons to group up in an environment which encourages the full development of their personality and of their physical and mental capacities, the Parties undertake . . . (1)(a) to ensure that children and young persons . . . have the care, the assistance, the education and the training they need.</p>	<p><b>ECSR:</b> held that France violated Article 15 and 17 because insufficient provision was made for the education of children and adults with autism. <i>International Association Autism-Europe v. France</i>, Complaint No. 13/2002.</p> <p><b>ECSR:</b> held that Bulgaria violated Article 17 “because children with moderate, severe or profound intellectual disabilities residing in HMDCs do not have an effective right to education,” and “because there is discrimination against children with moderate, severe or profound intellectual disabilities residing in HMDCs as a result of the low number of such children receiving any type of education when compared to other children.” <i>Mental Disability Advocacy Center (MDAC) v. Bulgaria</i>, Complaint No. 41/2007.</p>

**Other Interpretations**

**The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** 1993: States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system. [Standard Rules, 6].

**United Nations Guidelines for the Alternative Care for Children:** stating that children “should have access to formal, non-formal and vocational education in accordance with their rights, to the maximum extent possible in educational facilities in the local community.” (November 2009, para. 85).

**Council of Europe:** stating that “all children have rights, hence disabled children have the same rights to family life, education, health, social care and vocational training as all children; long-term planning involving all stakeholders will be needed to ensure that children with disabilities are able to exercise the same rights as other children and to access social rights on the same basis as other children.” (CM/Rec(2010)2).

**Table 9: Disability and the right to decent work**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• A person with intellectual disabilities is placed under guardianship, and the guardian does not allow him to be employed.</li> <li>• An employer refuses to hire a woman even though she is the best applicant for the job because she had depression in the past.</li> <li>• People with intellectual disabilities are ‘employed’ in a workshop where they are given menial tasks to do all day for which they receive ‘pocket money’ at the end of the week.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 27(1)</b> States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities...</p>	<p><b>CRPD:</b> recommending that <b>Spain</b> “develop open and advanced programs to increase employment opportunities for women and men with disabilities.” CRPD/C/ESP/CO/1 (CRPD, 2011).</p> <p><b>CRPD:</b> recommending that <b>Argentina</b> “develop a public policy to promote the inclusion of persons with disabilities in the labour market through, for example, the launch of awareness-raising campaigns targeting the private sector and the public at large which are designed to break down cultural barriers and prejudices against persons with disabilities, the implementation of reasonable adjustments in order to ensure that persons with disabilities in need of such adjustments can participate in the labour market, and the development of training and self-employment programmes. The Committee recommends that the State party reinforce its measures for monitoring and certifying compliance with the employment quota for persons with disabilities in the public sector.” CRPD/C/ARG/CO/1 (CRPD, 2012).</p> <p><b>CRPD:</b> recommending that <b>Hungary</b> “effectively implement the disability-specific provisions of the Labour Code and develop programmes to integrate persons with disabilities into the open labour market and the education and professional training systems, and to make all work places and educational and professional training institutions accessible for persons with disabilities.” CRPD/C/HUN/CO/1 (CRPD, 2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> “undertake all necessary measures to ensure the persons with disabilities freedom of choice to pursue vocations according to their preferences” and that it “create more working opportunities and enact legislature, so that companies and State organs employ more persons with disabilities.” CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> “introduce affirmative actions to promote the employment of persons with disabilities, inter alia, to prioritize the employment of persons with disabilities as civil servants.” CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>Peru</b> “develop new policies that promote the inclusion of persons with disabilities in the labour market which could include tax incentives for companies and persons who employ persons with disabilities, the recruitment of persons with disabilities in public administration and the development of self-employment programmes.” CRPD/C/PER/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>Tunisia</b> “Ensure the implementation of measures of affirmative action provided for in the law for the employment of women and men with disabilities” and “Increase the diversity of employment and vocational training opportunities for persons with disabilities.” CRPD/C/TUN/CO/1 (CRPD, 2011).</p>



**Table 9 (cont.)**

Human Rights Standards	Treaty Body Interpretation
<p><b>ICESCR 6 (1)</b> The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right. (2) The steps to be taken by a State Party . . . shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.</p>	<p><b>ICESCR General Comment 5</b>, para 21: recognizing “[t]he ‘right of everyone to the opportunity to gain his living by work which he freely chooses or accepts’ (Art 6(1)) is not realized where the only real opportunity open to disabled workers is to work in so-called ‘sheltered’ facilities under substandard conditions. Arrangements whereby persons with a certain category of disability are effectively confined to certain occupations or the production of certain good may violate this right.”</p>
<p><b>CEDAW 3</b> States Parties shall take in all fields, in particular in the political, social, economic and cultural fields, all appropriate measures, including legislation, to ensure the full development and advancement of women, for the purpose of guaranteeing them the exercise and enjoyment of human rights and fundamental freedoms on a basis of equality with men.</p>	<p><b>CEDAW Committee:</b> recommending that <b>Italy</b> “mainstream the issues of ... women with disabilities, who may suffer multiple forms of discrimination, into its employment policies and programmes, and to intensify its efforts ... aimed at achieving de facto equal opportunities for ... women with disabilities in the labour market.” CEDAW/C/ITA/CO/6 (CEDAW, 2011).</p> <p><b>CEDAW Committee:</b> recommending that <b>France</b> “undertake special measures to assist women with disabilities to enter into the labour market” CEDAW/C/FRA/CO/6 (CEDAW, 2008).</p>

**Other Interpretations**

**The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** 1993: States should actively support the integration of persons with disabilities into open employment. This active support should occur through a variety of measures such as vocational training, incentive-oriented quota schemes...financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities. [Standard Rules, Rule 7]

**Council of the Europe Resolution:** asking Member States to ‘continue efforts to remove barriers to the integration and participation of people with disabilities in the labor market, by enforcing equal treatment measures and improving integration and participation at all levels of the education and training system’ [2003/C175/01].

**Council of Europe:** Action Plan to promote the rights and full participation of people with disabilities in society (Europe 2006-2015): “To promote the employment of people with disabilities within the open labour market by combining anti-discrimination and positive action measures in order to ensure that people with disabilities have equality of opportunity.” (Recommendation (2006) 5 of the Committee of Ministers to member states on the Council of Europe).

**European Directive on Equal Treatment in Employment,** Council Directive 2000/78/EC

**European Union Charter,** art. 15: “Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation.”



**Table 10: Disability and the right to life**

Examples of Human Rights Violations	
<ul style="list-style-type: none"> <li>Terminating life support for persons with disabilities when such decisions are made on the basis of the person’s disability.</li> <li>Creating a distinctive period under the law that permits abortions solely on the basis of disability.</li> <li>Endangering a person with disabilities’ life (see the CRPD recommendation to China below).</li> </ul>	
Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 10</b> States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.</p>	<p><b>CRPD:</b> recommending that <b>Hungary</b> and <b>Spain</b> abolish the distinction made in the Act on the protection of the life of the fetus in the period allowed under law within which a pregnancy can be terminated, based solely on disability. CRPD/C/HUN/CO/1 (2012), CRPD/C/ESP/CO/1 (2011).</p> <p><b>CRPD:</b> expressing concern to <b>China</b> about the abduction of persons with intellectual disabilities, most of them children, and the staging of “mining accidents” in Hebei, Fujian, Liaoning and Sichuan, resulting in the victim’s death in order to claim compensation from the mine owners; urging that <b>China</b> continue investigating these incidents, prosecute all those responsible, impose appropriate sanctions, implement comprehensive measures to prevent further abductions of boys with intellectual disabilities and provide remedies to the victims. CRPD/C/CHN/CO/1 (2012).</p>
<p><b>CRPD 25</b> States shall ... (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.</p>	<p><b>CRPD:</b> expressing concern that, in <b>Spain</b>, guardians representing persons with disabilities deemed “legally incapacitated” may validly consent to termination or withdrawal of medical treatment, nutrition or other life support for those persons. The Committee reminded Spain that the right to life is absolute, and that substitute decision-making in regard to the termination or withdrawal of life-sustaining treatment is inconsistent with that right. Requested that Spain ensure that the informed consent of all persons with disabilities is secured on all matters relating to medical treatment, especially the withdrawal of treatment, nutrition or other life support. CRPD/C/ESP/CO/1 (2011).</p>

**Table II: Disability and the right to liberty and security of person**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Involuntary commitment to psychiatric institutions.</li> <li>• Individuals living with intellectual impairments are permanently confined at home because of lack of resources for medical and social care.</li> <li>• A young man is detained against his will to a psychiatric hospital after his parents raised concerns about his behaviour. He is not told why he has been admitted.</li> <li>• A woman is admitted to a social care home on the authorisation of the person appointed as her guardian. She is not consulted about this decision.</li> <li>• Residents of an institution are not informed about their right to apply to a court or tribunal to challenge their involuntary admission/detention.</li> <li>• There is no mechanism for appealing an involuntary commitment.</li> <li>• People are institutionalized indefinitely with no review of their status or of the admission decision.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 14 (1)</b> States Parties shall ensure that persons with disabilities, on an equal basis with others:</p> <p><b>(a)</b> Enjoy the right to liberty and security of person;</p> <p><b>(b)</b> Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.</p> <p><b>(2)</b> States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.</p>	<p><b>CRPD:</b> recommending that <b>Hungary</b> review provisions in legislation that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities. CRPD/C/HUN/CO/1 (2012).</p> <p><b>CRPD:</b> recommending that <b>China</b> abolish the practice of involuntary civil commitment based on actual or perceived impairment. CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> calling upon <b>Peru</b> to eliminate Law 29737 to prohibit the deprivation of liberty on the basis of disability, including psychosocial, intellectual or perceived disability. CRPD/C/PER/CO/1(2012).</p> <p><b>CRPD:</b> recommending that <b>Tunisia</b> repeal legislative provisions which allow for the deprivation of liberty on the basis of disability, including a psychosocial or intellectual disability. The Committee further recommended that until new legislation is in place, all cases of persons with disabilities who are deprived of their liberty in hospitals and specialized institutions be reviewed, and that the review include the possibility of appeal. CRPD/C/TUN/CO/1 (2011).</p> <p><b>CRPD:</b> recommending that <b>Spain</b> review its laws that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; the repeal of provisions that authorize involuntary internment linked to an apparent or diagnosed disability. CRPD/C/ESP/CO/1 (2011).</p>

**Table 12: Disability and protection against exploitation, violence and abuse**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• Students with disabilities experience higher rates of corporal punishment.</li> <li>• State systematically fails to prosecute persons responsible for violence and abuse against persons with disabilities.</li> <li>• State fails to develop a strategy to prevent violence against persons with disabilities in either private or public settings.</li> <li>• Programs and facilities servicing persons with disabilities are not monitored by independent authorities.</li> <li>• Persons with disabilities are subjected to forced labor.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 16 (1)</b> States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the, from all forms of exploitation, violence and abuse, including their gender-based aspects.</p> <p><b>(2)</b> States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.</p> <p><b>(3)</b> In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.</p> <p><b>(4)</b> States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.</p> <p><b>(5)</b> States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.</p>	<p><b>CRPD:</b> expressing concern to <b>Spain</b> that at the reportedly higher rates of abuse of children with disabilities in comparison with other children and recommending that Spain increase efforts to promote and protect the rights of children with disabilities, and to undertake research on violence against children with disabilities, adopting measures to eradicate this violation of their rights. CRPD/C/ESP/CO/1 (2011).</p> <p><b>CRPD:</b> recommending that <b>Hungary</b> take effective measures to ensure protection of women, men, girls and boys with disabilities from exploitation, violence and abuse, in accordance with the Convention, amongst others, the establishment of protocols for the early detection of violence, above all in institutional settings, procedural accommodation to gather testimonies of victims, and prosecution of those persons responsible, as well as redress for victims. It also recommends the State party to ensure that protection services are age-, gender- and disability-sensitive and accessible. CRPD/C/HUN/CO/1 (2012).</p> <p><b>CRPD:</b> expressing concern by the reported incidents of abduction and forced labor of thousands of persons with intellectual disabilities, especially children, such as the occurrence of slave labor in Shanxi and Henan; and urging <b>China</b> to continue investigating these incidents and prosecute the perpetrators. It also asked the state party to implement comprehensive measures to prevent further abductions of persons with intellectual disabilities and provide remedies to the victims, by including data collection on the prevalence of exploitation, abuse and violence against persons with disabilities. CRPD/C/CHN/CO/1 (2012)</p> <p><b>CRPD:</b> expressing concern to <b>Tunisia</b> regarding their high rate of violence for discipline in the home against boys and girls (94%) and recommending that Tunisia evaluate the phenomenon of violence against boys and girls with disabilities. CRPD/C/TUN/CO/1 (2011).</p> <p><b>CRPD:</b> encouraging <b>Tunisia</b> to include women and girls with disabilities in the National Strategy for the prevention of violence in the family and society, and to adopt comprehensive measures for them to have access to immediate protection, shelter and legal aid. It requested Tunisia to conduct awareness campaigns and develop educational programmes on the greater vulnerability of women and girls with disabilities with respect to violence and abuse. CRPD/C/TUN/CO/1 (2011).</p>

**Table 13: Disability and freedom from torture and cruel, inhuman and degrading treatment**

Examples of Human Rights Violations
<ul style="list-style-type: none"> <li>• People in an institution are kept in cage beds and are forced to eat and use the toilet in bed.</li> <li>• People in an institution who have been labeled “dangerous” by staff are tied or chained to chairs or beds for hours and even days at a time.</li> <li>• Persons with disabilities are subjected to “correctional therapy” at psychiatric institutions.</li> <li>• Persons with disabilities are involuntarily administered psychiatric medication including neuroleptics.</li> </ul>

Human Rights Standards	Treaty Body Interpretation
<p><b>CRPD 15 (1)</b> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.</p>	<p><b>CRPD:</b> noting that in <b>China</b> “For those involuntarily committed persons with actual or perceived intellectual and psychosocial impairments, the Committee is concerned that the “correctional therapy” offered at psychiatric institutions represents inhuman and degrading treatment. Further, the Committee is concerned that not all medical experimentation without free and informed consent is prohibited by Chinese law.” Urging <b>China</b> “to cease its policy of subjecting persons with actual or perceived impairments to such therapies and abstain from involuntarily committing them to institutions” and “to abolish laws which allow for medical experimentation on persons with disabilities without their free and informed consent.” CRPD/C/CHN/CO/1 (2012).</p> <p><b>CRPD:</b> urging <b>Peru</b> to “promptly investigate the allegations of cruel, inhuman or degrading treatment, or punishment in psychiatric institutions, to thoroughly review the legality of the placement of patients in these institutions, as well as to establish voluntary mental health treatment services, in order to allow the persons with disabilities to be included in the community and release them from the institutions.” CRPD/C/PER/CO/1 (2012).</p> <p><b>CRPD:</b> urging <b>Argentina</b> “to immediately approve the bill on the creation of a national mechanism for the prevention of torture so that institutionalized persons with disabilities can be monitored and protected from actions that may constitute acts of torture or other forms of cruel, inhuman or degrading treatment or punishment.” CRPD/C/ARG/CO/1 (CRPD, 2012)</p> <p><b>CRPD:</b> urging <b>Hungary</b> to “amend Act CLIV on Healthcare and abolish the provisions thereof that provide for a legal framework for subjecting persons with disabilities with restricted legal capacity to medical experimentation without their free and informed consent.” CRPD/C/HUN/CO/1 (CRPD, 2012)</p>

### 3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

#### What is a human rights-based approach?

*“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”<sup>96</sup>*

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights. Human rights principles include: “universality and inalienability; indivisibility; interdependence and inter-relatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”<sup>97</sup> They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.

Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).<sup>98</sup> With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”<sup>99</sup>

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

<sup>96</sup> Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

<sup>97</sup> For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: [www.undg.org/archive\\_docs/6959-The\\_Human\\_Rights\\_Based\\_Approach\\_to\\_Development\\_Cooperation\\_Towards\\_a\\_Common\\_Understanding\\_among\\_UN.pdf](http://www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf).

<sup>98</sup> Ibid.

<sup>99</sup> Ibid.

## What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

## Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.<sup>100</sup> Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

<sup>100</sup> Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

## How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.



## 4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS PROGRAMMING IN THE AREA OF DISABILITY, HEALTH AND COMMUNITY LIVING?

This section contains **eight examples** of effective activities addressing disability and human rights. These are:

1. Studies on disability-related harassment
2. The first decision of the Committee on the Rights of Persons with Disabilities
3. Challenging educational opportunities for autistic children in France
4. Advocating for the rights of persons with intellectual disabilities in Kenya
5. Advocating for the implementation of the CRPD in Croatia
6. Advocating for independent living for persons with disabilities in Europe
7. Establishing community-based supported housing in Moldova
8. Implementing supported decision making in Canada

## Example I: Studies on Disability-Related Harassment

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### Project Type

Advocacy

### The Organization

Established in 2007 by the British Government, the Equality and Human Rights Commission now promotes and monitors human rights across nine protected grounds. Under the Equality Act of 2006, the Equality and Human Rights Commission is charged “with a view to encouraging and supporting the development of a society in which (a) people’s ability to achieve their potential is not limited by prejudice or discrimination, (b) there is respect for and protection of each individual’s human rights, (c) there is respect for the dignity and worth of each individual, (d) each individual has an equal opportunity to participate in society, and (e) there is mutual respect between groups based on understand and valuing of diversity and on shared respect for equality and human rights.” Equality Act, 2006, c. 3, § 3 (Eng, Wales and Scot).

### The Problem

People with disabilities are often targets of harassment and violence and in many cases the violence results in death or serious injury. However, harassment and hate crimes against persons with disabilities are largely undocumented and as such remain invisible to society. In cases where persons with disabilities are harassed to the point of serious injury, authorities have been often aware of earlier, less serious incidents of harassment but failed to take adequate precautions. Sometimes authorities disregard or disbelieve reports of violence against persons with disabilities or sometimes they fail to share information with other relevant organizations. Often authorities seek to change the victim’s behavior rather than addressing the perpetrator’s behavior. Also, people with disabilities do not always report violence against them for many factors including social isolation. When harassment progresses to degrading and dehumanizing treatment, authorities often fail to classify this behavior as a hate crime as they would for other protected characteristics.

### Actions Taken

The Equality and Human Rights Commission conducted an inquiry into the everyday experiences of persons with disabilities who were subject to harassment. The inquiry featured ten selected cases where persons with disabilities have died or been seriously injured as a result of disability-related harassment. The inquiry utilized the ten selected cases to illustrate the key features of disability-related harassment. Each case involved an in depth examination to explore how and why disability-related harassment occurs. The inquiry engaged with authorities involved with each of the cases leading to open dialogue about the breakdown in protection of the individual. After reviewing all of the materials and analyzing the common features, the inquiry developed seven core recommendations and 79 detailed recommendations. The Equality and Human Rights Commission then published the recommendations for public consultation through which they received 81 formal responses. Based upon these, the Commission released a second report detailing 43 final recommendations under seven categories.

### Results & Lessons Learned

The inquiry and report are valuable on many levels. The inquiry enabled authorities involved in cases of pervasive harassment to reflect on their role of protecting persons with disabilities and how this may best be accomplished. As well, the inquiry made public issues of disability-related harassment and the gross violations of rights that occur against persons with disabilities in Great Britain. Lastly, the inquiry and report develop positive recommendations that will be helpful in guiding further discussion and policy reform in the area of disability-related harassment.

## **Hidden in Plain Sight: Inquiry into disability-related harassment (2011)**

Available at: [http://www.equalityhumanrights.com/uploaded\\_files/disabilityfi/ehrc\\_hidden\\_in\\_plain\\_sight\\_3.pdf](http://www.equalityhumanrights.com/uploaded_files/disabilityfi/ehrc_hidden_in_plain_sight_3.pdf)

## **Out in the open: Tackling disability-related harassment: A manifesto for change (2012)**

Available at: <http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-in-to-disability-related-harassment/out-in-the-open-manifesto-for-change/>

The recommendations are categorized under the following seven categories:

1. **Reporting, recording and recognition** to counter that “underreporting of disability-related harassment was widespread; that disabled people often saw incidents as so commonplace as to be part of daily life and not ‘hate crimes’ and that those receiving reports of harassment were failing to ask about disability or see it as a potential motivation.”
2. **Addressing gaps in legislation and policy** to counter “disparity in sentencing guidelines for different groups and an insufficiently robust safeguarding referral process that means people are put at risk and criminal acts are not promptly referred to the police.”
3. **Ensuring adequate support and advocacy** to counter “gaps in provision of support services, not just at the reporting stage but throughout and beyond the process of accessing justice.”
4. **Improved practice and shared learning** to prevent “problems with sharing data, failure to recognize ‘incidents’ and a failure to pick up incidents at an early stage.”
5. **Redress and accessing justice** to counter that “very few cases of disability-related harassment go through the courts; and even when they do, sentencing does not always follow.”
6. **Prevention, deterrence and understanding motivation** to counter “a lack of investment in research into the motivation and profile of perpetrators” and the lack of “statutory requirement to conduct a serious case review for the murder of a disabled person.”
7. **Transparency, accountability and involvement** to counter “that the absence of data is a major problem to identifying, preventing and tackling disability-related harassment” and that it also “makes it harder for individuals and organizations at a local level to hold authorities to account for their performance.”

**Equality and Human Rights Commission**  
Great Britain  
Web: <http://www.equalityhumanrights.com/>

## Example 2: The first decision of the Committee on the Rights of Persons with Disabilities

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### Project Type

Litigation: *H.M. v. Sweden*, U.N. Doc. CRPD/C/7/D/3/2011 (21 May 2012).

### The Actor

H.M., a private litigant with a disability, brought this case.

### The Problem

H.M. had disability that limited her mobility. Her doctors determined that hydrotherapy was the only option to stop her physical impairments from progressing further and improve her quality of life. However, because she could not leave her house without risk of further injury, the doctors recommended the construction of an indoor pool in her home for hydrotherapy.

H.M. applied for a permit with the Örebro Local Housing Committee to extend her house by 63 square meters so that she could build an indoor pool. The Housing Committee rejected H.M.'s application because the *Planning and Building Act* prohibited such a use.

### Procedure

H.M. appealed the decision and exhausted her domestic remedies. She then filed a complaint with the Committee on the Rights of Persons with Disabilities.

### Arguments & Holdings

#### *Article 2—Definition*

Article 2(3) of the CRPD prohibits “discrimination on the basis of disability.” The Committee reasoned that “denial of reasonable accommodation” was included by the definition of “discrimination on the basis of disability.” Furthermore, and quite importantly, the Committee found:

*The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention can be violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different.*

The Committee found that the applicant's hydrotherapy pool was essential to prevent the advancement of H.M.'s physical impairments, which stemmed from her disability. Therefore, since a departure from the development plan under the Planning and Building Act would not be a “disproportionate or undue burden,” the CRPD required that Sweden make the departure so that H.M. may build her therapeutic pool.

*Articles 25 (health) & 26 (habilitation and rehabilitation)*

Article 25 of the CRPD provides that persons with disabilities have the right to health “without discrimination on the basis of disability” and that “States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services . . . including health-related rehabilitation.” Article 26 of the CRPD provides that “States Parties shall take effective and appropriate measures . . . to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life.” In light of Articles 25 and 26, the Committee found that the denial of development plan departure permit was disproportionate and produced a discriminatory effect on a person with a disability who needed the permit for health and habilitation. Therefore, the Committee found a violation of Articles 25 and 26 of the CRPD.

*Article 19(b) (Living independently and being included in the community).*

Article 19 of the CRPD imposes an obligation on States Parties to “take effective and appropriate measures” to “facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.” The Article specifically states that “[p]ersons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.” Therefore, the Committee found that Sweden had violated Article 19(b) of the CRPD, since the therapeutic pool was the “only option that could support her living [in] and inclusion in the community.”

## **Convention on the Rights of Persons with Disabilities (CRPD)**

### **Article 2**

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

### **Article 25 (health)**

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

### **Article 26 (habilitation and rehabilitation)**

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services ...

### **Article 19 (community living)**

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community ...

### **Commentary & Analysis**

This is the first decision of the U.N. Committee on the Right of Persons with Disabilities. It also marks a break from the medical legal model to the social legal model for disability issues. Understanding that it is not the person that is deficient, but rather the environment, the CRPD rejects a medical model in favor of a social model that puts an end to barriers that prevent participation in society by persons with disabilities.

#### **Jurisprudence from Committee on the Rights of Persons with Disabilities**

Web: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Jurisprudence.aspx>

## Example 3: Challenging educational opportunities for children with autism in France

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### Project Type

Litigation

### The Organization

Autism-Europe is a European umbrella organisation whose main objective is to advance the rights of persons with autism and their families and to help them improve their quality of life. They cooperate with various other civil society organizations, such as the European Disability Forum (EDF) and the Platform of European Social NGOs to influence European decision-makers.

### The Problem

At the time this action was filed, France was failing to provide education to people with autism due to (1) the lack of inclusion of people with autism in mainstream education on the one hand and (2) the dramatic shortage of specialised educational services on the other hand.

When Autism-Europe lodged the complaint, only 10% of children and adults requiring specialized education were enrolled in a special school. The other 90% were not receiving any education.

In addition, only 5% of the children with autism who could have been mainstreamed were individually integrated into schools.

### Procedure

In 2002, Autism Europe submitted a collective complaint to the European Committee of Social Rights on the ground of Articles 15, 17 and E of the European Social Charter, dealing with insufficient educational provision for persons with autism in France. In 2003 the European Committee rendered its decision.

### Arguments & Holding

According to Autism Europe, France failed to satisfactorily apply its obligations under the Revised European Social Charter with regard to the right to education of children and adults with autism. In this respect, Autism-Europe argued that France did not provide sufficient education opportunities, facilities and services of an adequate standard or quality to children and adults with autism. Additionally, Autism-Europe claimed that France discriminated against children and adults with autism because France did not manage to ensure that they enjoyed the right to education in the same way that all other children and adults did. This lack of action by the French government also resulted in discrimination because children and adults with autism did not enjoy the same level of education as other people.

The European Committee of Social Rights concluded that the situation in France constituted a violation of Articles 15§1 and 17§1, and of Article E of the revised European Social Charter because:

- (1) the proportion of children with autism being educated in either general or specialist schools in France is much lower than in the case of other children, whether or not disabled, and
- (2) there is a chronic shortage of care and support facilities for autistic adults.



## Violations of the Revised European Social Charter

**Article 15** - The right of persons with disabilities to independence, social integration and participation in the life of the community.

**Article 17** – The right of children and young persons to social, legal and economic protection.

**Article E** – Non-discrimination principle

### Committee's Application of the Charter to the Facts

“[T]he implementation of the Charter requires the State Parties to take not merely legal action but also practical action to give full effect to the rights recognised in the Charter. When the achievement of one of the rights in question is exceptionally complex and particularly expensive to resolve, a State Party must take measures that allow it to achieve the objectives of the Charter within a reasonable time, with measurable progress and to an extent consistent with the maximum use of available resources. States Parties must be particularly mindful of the impact that choices will have for groups with heightened vulnerabilities as well as for others [sic] persons affected including, especially their families on whom falls the heaviest burden in the event of institutional shortcomings”

### Commentary & Analysis

Even though the decision referred specifically to the case of people with autism, its scope goes well beyond this group by reasserting the right to education for all people with disabilities, regardless of the severity of the disability. While people with autism are unfortunately the hardest hit because of the glaring lack of educational services tailored for their needs, they unfortunately are not the only ones to suffer because of France's indigence in this regard.

Autism Europe's complaint is the first collective action to defend the rights of people with disabilities in Europe. Its importance in this respect was highlighted by the Council of Europe. This action culminated in a decision that was adopted in 2003, which was the European Year of People with Disabilities. It took its place in the movement to improve the fundamental rights of people with disabilities, especially of those in need of a high level of support, throughout Europe.

The lack of education could also be challenged by the UN Convention on the Rights of Persons with Disabilities, since States Parties recognize the right of persons with disabilities to education and to effective individualized support.

#### **Autism Europe**

Brussels, Belgium

E-mail: [secretariat@autismeurope.org](mailto:secretariat@autismeurope.org)

Web: <http://www.autismeurope.org/>

## Example 4: Advocating for the rights of persons with intellectual disabilities in Kenya

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### Project Type

Advocacy

### The Organization

Founded in 1996 as a teacher-based organization, the Kenya Association for the Intellectually Handicapped (KAIH) is committed to the promotion of the welfare of the intellectually handicapped. The mission of KAIH is “[t]o promote the human rights of [persons with intellectual disabilities] and their families within society through education, advocacy, empowerment, and information exchange.”

### The Problem

Persons with intellectual disabilities in Kenya face higher incidences of sexual, physical, emotional and psycho-social abuse than the general population. As a result, they are more vulnerable to HIV/AIDS.

Only 1% of persons with intellectual disabilities in Kenya have their Kenyan National Identification Card. Consequently, obtaining benefits and asserting rights based on citizenship is quite difficult. Additionally, only 1.5-2% of persons with intellectual disabilities attend primary school, and they therefore have fewer employment opportunities than the general population that attends school at a higher rate.

Most of these problems are traceable to widespread discrimination and stigma within Kenya against persons with intellectual disabilities and the lack of knowledge that persons with intellectual disabilities have of their own rights.

### Actions Taken

In 2004, KAIH began to shift its focus away from training teachers to educating parents and supporting the home life of children with intellectual disabilities. KAIH formed parent support groups to teach parents about their child’s intellectual disabilities.

In addition, KAIH informs children with intellectual disabilities of their human rights. Armed with knowledge, children with disabilities can now use a rights-based approach for self-advocacy.

Finally, KAIH has worked to educate the community about intellectual disabilities to counter the prevalent stigma and discrimination that exists against persons with intellectual disabilities.

### Results & Lessons Learned

There are now 42 different support groups throughout the Migori, Nyeri, Kiambu, Siaya and Nairobi counties. Each county has its own list of accomplishments, including those related to education awareness creation, advocacy, self-advocacy, economic, social and political change; HIV/AIDS and reproductive health; vocational rehabilitation and sustainable livelihoods; resource mobilization; and institutional strengthening and governance. You may find a list of each county's accomplishments here:

- Nyeri (<http://tinyurl.com/b4gm6rn>)
- Siaya (<http://tinyurl.com/b7jbnx6>)
- Migori (<http://tinyurl.com/a5r4xjc>)
- Nairobi (<http://tinyurl.com/ax73gx9>)
- Kiambu (<http://tinyurl.com/bxg8pju>).

In 2011, KAIH won the social inclusion category at the inaugural Ability Awards, Kenya's first awards ceremony for organizations and people advancing the rights of persons with disabilities. KAIH's work advocating for persons with disabilities was nationally recognized at the Ability Awards.

#### **Kenya Association of the Intellectually Handicapped (KAIH)**

Nairobi, Kenya

Web: <http://kaihid.org/>

## Example 5: Advocating for the Implementation of the CRPD in Croatia

### Project Type

Advocacy

### The Organization

The Association for Self Advocacy (ASA), established in 2003, is the first non-governmental organization (NGO) in Croatia run by and for persons with intellectual disabilities.

### The Problem

Croatia was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities (CRPD), yet persons with intellectual disabilities remain marginalized in Croatian society. Many persons with intellectual disabilities in Croatia are declared legally incompetent and thus denied the right to make any decisions regarding their lives. As a result, many cannot realize their right to education, employment, marriage, ownership of property, voting, or other basic rights. One in three children and adults with severe intellectual disabilities in Croatia remains institutionalized.

### Actions Taken

The CRPD has the potential to introduce significant improvements in the lives of persons with intellectual disabilities. The ASA undertakes a variety of activities aimed at promoting the implementation the CRPD:

- ASA advocates for the development of community-based services as alternatives to institutionalization.
- ASA trains persons with intellectual disabilities about human rights and self-advocacy, and organizes public awareness campaigns about the human rights of people with intellectual disabilities.
- Consistent with the CRPD's guarantee of accessibility, ASA prepares and distributes easy-to-read materials on the rights of persons with intellectual disabilities.

### In Focus

Although Croatia is a state party to the CRPD, its progress towards meeting its obligations under that convention and towards deinstitutionalization of the intellectually disabled has been disappointing. According to Human Rights Watch, “research in Croatia found a serious lack of progress with regard to deinstitutionalization, combined with limited investment in development and financing of community-based alternatives to institutional care and housing . . . . [T]he primary reason for the failings described . . . is not lack of financial resources dedicated to deinstitutionalization but rather lack of leadership.” NGOs, like the ASA, are necessary to narrow the gap between Convention obligations and the realization of rights for persons with disabilities.

Source: Human Rights Watch, *Once You Enter, You Never Leave: Deinstitutionalization of Persons with Intellectual or Mental Disabilities in Croatia* 2, 51 (September 2010). Available at: <http://www.hrw.org/reports/2010/09/23/once-you-enter-you-never-leave-o>.

### Results & Lessons Learned

- ASA, led by persons with intellectual disabilities, is recognized for its expertise in human rights and advocacy.
- Persons with intellectual disabilities in Croatia, Slovenia, Bosnia and Herzegovina, Macedonia and Romania who have participated in ASA's self-determination and self-advocacy training are equipped with the skills to advocate for their rights in their respective countries.
- ASA works with other self advocacy groups, human rights organizations and NGOs providing community based services for persons with intellectual disabilities to promote implementation of the CRPD.

**Association for Self-Advocacy (ASA)**  
**Udruga za samozastupanje** (Croatian)  
Zagreb, Croatia  
E-mail: [kontakt@samozastupanje.hr](mailto:kontakt@samozastupanje.hr)  
Web: <http://www.samozastupanje.hr/>

## Example 6: Advocating Across Europe for Independent Living for Persons with Disabilities

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### Project Type

Advocacy

### The Organization

In 2005, a group of advocacy organizations established the European Coalition for Community Living (ECCL) to advocate for the development of comprehensive, quality, community-based services as an alternative to institutionalization. A Europe wide cross-disability initiative, ECCL is led by the European Network on Independent Living, the European umbrella organization run by people with disabilities.

### The Problem

Over one million people with disabilities are confined to long-stay institutions across Europe, often for their entire life. Despite recognition that people with disabilities have the right to live in the community as equal citizens, the legal, financial, and other reforms necessary for community living have not been implemented. The development of a wide range of quality community-based alternatives to institutionalization is crucial to realizing community-based living for all people with disabilities.

### Actions Taken

ECCL's activities include:

- *Publishing* position papers and briefings and making recommendations on the right of people with disabilities to live in the community.
- *Advocating* before European institutions for policies that support community-based services, and highlighting the crucial importance of involving people with disabilities as equal partners in this work.
- *Supporting* ECCL members in their national advocacy activities.
- *Facilitating* exchange of information and the promotion of best practice in the development of community based services, through seminars and newsletters for ECCL members and other interested organizations.
- *Launching* a campaign calling for recognition of the right of all people with disabilities to live in the community and for a shift in government funding from long stay institutions to community-based services.

- *Publishing* an investigative article and video that highlights the appalling human rights abuses that take place on a daily basis in institutions for people with disabilities in Bulgaria, Romania and Serbia. The article and video also document the lack of real progress towards developing community-based alternatives.
  - Yana Buhner et al., *Institutions Remain Dumping Grounds for Forgotten People*, Newsletter of the European Coalition for Community Living (Issue No. 10), Oct. 2009, at 3. Available at: [http://www.opensocietyfoundations.org/sites/default/files/eccl\\_20091031.pdf](http://www.opensocietyfoundations.org/sites/default/files/eccl_20091031.pdf).
- Writing a report, which found that recipients of European Union’s Structural Funds maintain large, archaic institutions for people with disabilities with the funds they receive, instead of using those funds to support community-based programs.
  - European Coalition for Community Living (ECCL), *Wasted Time, Wasted Money, Wasted Lives—A Wasted Opportunity?* (2010). Available at: <http://www.opensocietyfoundations.org/sites/default/files/wasted-opportunity-20100325.pdf>.
  - Video: *Dumping Grounds for Forgotten People* (Nov. 3, 2009). Available at: [http://www.youtube.com/watch?feature=player\\_embedded&v=R\\_juS3m0534](http://www.youtube.com/watch?feature=player_embedded&v=R_juS3m0534).
- Contributing to the work of the European Expert Group on the Transition from Institutional to Community-based Care, established in 2009 at the initiative of the European Commission. Within this group, ECCL made a significant contribution to three policy documents, and has taken part in trainings on the right to community living and developing community-based alternatives to institutional care for the European Commission and national governments.
  - Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009). Available at: <http://ec.europa.eu/social/main.jsp?langId=ro&catId=89&newsId=614&furtherNews=yes>.
  - Common European Guidelines on the Transition from Institutional to Community-based Care (2012) and the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care. Available at: [www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu).

### Results & Lessons Learned

- ECCL has provided organizations with information and contacts in planning, providing or advocating for community-based services.
- ECCL has established cooperation with policy and decision makers at the European level and is considered to be an expert on community living and deinstitutionalization by various European disability organizations.
- By insisting on the central role of people with disabilities in the planning and delivery of services, ECCL has gained the trust of user-led organizations and is considered a legitimate representative of their interests.

#### European Coalition for Community Living (ECCL)

E-mail: [coordinator@community-living.info](mailto:coordinator@community-living.info)

Web: [www.community-living.info](http://www.community-living.info)



## Example 7: Establishing Community-Based Supported Housing and Support Services in Moldova

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**Project Type**  
Advocacy

### **The Organization**

Keystone Human Services International (KHSI) is a family of non-profit, non-governmental organizations, including working to create environments where all people can grow, exercise self determination and be participating, contributing and valued members of their communities. Through subsidiaries in Eastern Europe, including the Moldova Association (KHSMA), KHSI advances the independence of people in vulnerable situations due to disability, institutionalization, poverty, abandonment and exploitation.

Keystone Human Services International Moldova Association (KHSIMA), a non-governmental organization that promotes the human rights and social inclusion of people with intellectual disabilities,

### **The Problem**

In Moldova, as in many Central and Eastern European countries, many persons with intellectual disabilities are placed in long-stay institutions with little or no contact with their families or communities. A major reason for this is the lack of alternative services and support at the community level.

### **Actions Taken**

KHSIMA has worked effectively with the Ministry of Labor and Social Welfare to establish community-based supported housing and other support services as alternatives to institutionalization. KHSIMA's work includes:

- Developing pilot community-based alternatives to institutions, focusing on supported housing, shared living, family reunification, and foster care.
- Providing technical assistance for the development of legislation and financial mechanisms for community-based services.
- Documenting the deinstitutionalization process as tool for learning and replication and developing an evidence-base for deinstitutionalization in Moldova.

### Results & Lessons Learned

- KHSIMA's work has shown that it is possible for non-governmental organisations to develop good quality community based services and to have a significant influence on policy and service development.
- KHSIMA's pilot community-based alternatives have been recognized by the Ministry of Labor and Social Welfare for their quality, and have helped to make deinstitutionalization and the development of community based services a Ministry priority, with KHSIMA a key Ministry partner.
- Policy and legislation for community-based services informed by implementing deinstitutionalization was adopted.

#### **Keystone Human Services International Moldova Association (KHSIMA)**

Chisinau, Moldova

E-mail: [khsima@keystonehumanservices.org](mailto:khsima@keystonehumanservices.org)

Web: <http://www.keystonemoldova.md>

## Example 8: Implementing Supported Decision Making Through “Representation Agreements” in Canada

### Project Type

Advocacy

### The Organization

Founded by citizens and community groups involved in the reform of British Columbia’s adult guardianship legislation, the Nidus Personal Planning Resource Centre is a non-profit, charitable organization operating in British Columbia, Canada. Nidus helps persons with disabilities engage in personal planning in the areas of health care, personal care, legal affairs and financial affairs. Their website includes fact sheets, videos, legal forms and exercises that help advance supported decision making through representation agreements, enduring powers of attorney, health care consent, advance directives, living wills, personal care, adult guardianship and the prevention of abuse.

### The Problem

Most states have a system by which a court can declare a person legally incompetent. Under these systems, many persons with mental disabilities lose their legal capacity to make decisions for themselves, sign contracts, vote, defend themselves in court or make their own health care decisions. Yet, Article 12 of the Convention on the Rights of Persons with Disabilities recognizes that persons with disabilities have the right to equal legal capacity. Therefore, it is necessary for State Parties to enact legislation or provide programs to provide assistance to persons with disabilities so that they may exercise this capacity.

## Supported Decision-Making

A decision making approach according to which supporters, advocates or established systems may assist an individual with disability to make his or her own decision or express his or her will, provided the supporter, advocate or system is not in conflict of interest or in a position of power or undue influence over the individual. Supported decision making, as opposed to traditional substitute decision-making or guardianship, does not imply a transfer of decision making rights to third a party.

## Convention on the Rights of Persons with Disabilities (CRPD)

**Art. 12(2):** States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

**Art. 12(3):** States Parties shall take appropriate measures to provide access by persons with disabilities to support they may require in exercising their legal capacity.

### Actions Taken

British Columbia enacted the Representation Agreement Act, which allows disabled persons with diminished mental capacity to enter into a representation agreement with a “support network”, which empowers them to make their own decisions when possible by providing them with interpretative and communicative assistance. As noted by the UN:

*One of the main innovations in the legislation is that [it does not define capacity, meaning that] persons with more significant disabilities [do not have to meet specific criteria to] enter into representation agreements with a support network . A person does not need to prove legal competency under the usual criteria, such as having a demonstrated capacity to understand relevant information, appreciate consequences, act voluntarily and communicate a decision independently, in order to enter this agreement.*

*A number of individuals and support networks have entered representation agreements as an alternative to guardianship or other forms of substitute decision-making. A community-based Representation Agreement Resource Centre [Nidus] assists in developing and sustaining support networks by providing information, publications, workshops and advice. The Centre also oversees a registry in which a network can post an agreement for other parties to view if required before entering a contract with the individual.*

### Representation Agreement Act, RSBC 1996, c 405 (Can.).

<http://www.canlii.org/en/bc/laws/stat/rsbc-1996-c-405/latest/rsbc-1996-c-405.html>

### Results & Lessons Learned

For many years, States have assumed that the mere status of having an intellectual or psychological disability provides sufficient basis to strip a person of his/her legal capacity to exercise his/her rights. This new legislation from British Columbia represents a paradigm shift away from a paternalistic-oriented substituted decision making legal scheme towards a supported decision-making which respects the legal capacity of disabled persons. It is a reflection of the Preamble of the CRPD, which recognizes “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices” and that “persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.”

#### **Nidus Personal Planning Resource Centre and Registry**

Vancouver, Canada

E-mail: [info@nidus.ca](mailto:info@nidus.ca)

Web: [www.nidus.ca](http://www.nidus.ca)

## 5. WHERE CAN I FIND ADDITIONAL RESOURCES ON DISABILITY AND HUMAN RIGHTS?

A list of commonly used resources on disability and human rights follows. It is organized into the following categories:

- A. International instruments
- B. Regional instruments – Europe
- C. Regional instruments – Other
- D. Disability and Human Rights – General
- E. Health Care and Disability
- F. Disability and Reproductive and Sexual Health
- G. Education and Disability
- H. Torture, Violence and Abuse and Disability
- I. Women and girls with Disabilities
- J. Children with Disabilities
- K. HIV/AIDs and Disability
- L. Disability and Development
- M. Community Living – Generally
- N. Community Living – Europe
- O. Supported Decision-Making
- P. Resources / Periodicals
- Q. Toolkits
- R. Websites - General
- S. Websites – Community Living

### Research Tips

A good starting point for general information on the CRPD is the UN Enable website (<http://www.un.org/disabilities/>). This is the official website of the Secretariat for the Convention on the Rights of Persons with Disabilities located within the UN Department of Economic and Social Affairs. This website features recent events and publications from UN sources as well as information, publications and links on thematic areas relating to disability and human rights. The home page also provides an option to sign up for the UN Enable Newsletter.

The UN Committee on the Rights of Persons with Disabilities also maintains a website (<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>) with links to its latest events, reports, jurisprudence and external links.

## A. International instruments

- International Labour Organization (ILO), *Managing Disability in the Workplace* (ILO Code of Practice, 2001). [http://www.ilo.org/wcmsp5/groups/public/---ed\\_emp/documents/publication/wcms\\_103324.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_emp/documents/publication/wcms_103324.pdf).
- International Labour Organization (ILO), *Convention (No. 159) and Recommendation (No. 168) Regarding Vocational Rehabilitation and Employment* (2008). [http://www.ilo.org/wcmsp5/groups/public/---ed\\_emp/---ifp\\_skills/documents/publication/wcms\\_103529.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_103529.pdf).
- UN Committee on Economic, Social and Cultural Rights, *General Comment 5: Persons with Disabilities* (1994). <http://www2.ohchr.org/english/bodies/cescr/comments.htm>.
- UN Committee on the Elimination of Discrimination against Women, *Recommendation No. 18: Disabled Women* (1991). <http://www2.ohchr.org/english/bodies/cedaw/comments.htm>.
- UN Committee on the Rights of the Child, *General Comment 9: The rights of children with disabilities* (2006). <http://tb.ohchr.org/default.aspx?Symbol=CRC/C/GC/9>.
- UN General Assembly, *Beijing Declaration on the Rights of People with Disabilities* (2000).
- UN General Assembly, *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, UN Document A/RES/48/96 (December 20, 1993). <http://www.un.org/documents/ga/res/48/a48ro96.htm>.
- UN General Assembly, *Guidelines for the Alternative Care of Children*, UN Document A/RES/64/142 (February 24, 2010). [http://www.unicef.org/protection/alternative\\_care\\_Guidelines-English.pdf](http://www.unicef.org/protection/alternative_care_Guidelines-English.pdf).

## B. Regional Instruments - Europe

- European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, COM/2010/0636 (November 2010). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOT>.
- European Council, *Council Directive establishing a General Framework for Equal Treatment in Employment and Occupation* [Equality Employment Framework Directive], 2000/78/EC (November 27, 2000). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:en:HTML>.
- Council of Europe, *Recommendation of the Committee of Ministers to member states on achieving full participation through Universal Design*, CM/Rec(2009)8 (October 21, 2009). <https://wcd.coe.int/ViewDoc.jsp?id=1526681&Site=CM>.
- Council of Europe, *Recommendation of the Committee of Ministers to member states on ageing and disability in the 21st century: sustainable frameworks to enable a greater quality of life in an inclusive society*, CM/Rec (2009)6 (July 8, 2009). <https://wcd.coe.int/ViewDoc.jsp?id=1470069&Site=CM>.
- Council of Europe, *Recommendation of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015* [Council of Europe Disability Action Plan 2006-2015], CM/Rec(2006)5 (April 5, 2006). <https://wcd.coe.int/ViewDoc.jsp?id=986865>.
- Council of Europe, *Recommendation of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities*, CM/Rec(2010)2 (February 3, 2010). <https://wcd.coe.int/ViewDoc.jsp?id=1580285&Site=CM>.

- Council of Europe, *Recommendation of the Committee of Ministers to member states on the education and social inclusion of children and young people with autism spectrum disorders*, CM/Rec(2009)9 (October 21, 2009). <https://wcd.coe.int/ViewDoc.jsp?id=1526657&Site=CM>.
- Council of Europe, *Recommendation of the Committee of Ministers to member states on the rights of children living in residential institutions*, Rec(2005)5 (March 16, 2005). <https://wcd.coe.int/ViewDoc.jsp?id=835953&Site=CM>.
- Council of Europe: Committee on the Rehabilitation and Integration of People with Disabilities, *Recommendations and Guidelines to promote community living for children with disabilities and deinstitutionalization, as well as to help families to take care of their disabled child at home* (December 31, 2007).
- Council of Europe, European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), *CPT Standards: European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT)*, CPT/Inf/E(2002)1 – Rev. 2011 (2011), pp. 48-63. [www.cpt.coe.int/en/documents/eng-standards.doc](http://www.cpt.coe.int/en/documents/eng-standards.doc).
- Council of Europe, Parliamentary Assembly, *Recommendation 1592: Towards full social inclusion of people with disabilities* (January 29, 2003). <http://assembly.coe.int/main.asp?Link=/documents/adoptedtext/tao3/erec1592.htm>.
- European Parliament, *Resolution on the Commission's communication on equality of opportunity for people with disabilities*, Official Journal C 132, 28/04/1997 P. 0313 (1996). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:51997IP0044:EN:HTML>.
- European Parliament, *Resolution on Threats to the Right to Life of Disabled Persons*, Official Journal C 166, 10/06/1996 P. 0205 (1996). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:51996IP0650:EN:HTML>.
- European Parliament, *Resolution on the Human Rights of Disabled People*, Official Journal C 017, 22/01/1996 P. 0196 (1995). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:51995IP1494:EN:HTML>.
- WHO Regional Office for Europe, *European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families*, adopted at conference “Better health, better lives: children and young people with intellectual disabilities and their families,” Document EUR/51298/17/6 (November 26-27, 2010). [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0015/121263/e94506.pdf](http://www.euro.who.int/__data/assets/pdf_file/0015/121263/e94506.pdf).

## C. Regional Instruments - Other

- Organization of American States, *Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities* (June 7, 1999). <http://www.oas.org/juridico/english/treaties/a-65.html>.
- Organization of American States, *Program of Action for the Decade of the Americas for the Rights and Dignity of Persons with Disabilities 2006-2016*, Document AG/RES 2230 (2006). [http://scm.oas.org/doc\\_public/ENGLISH/HIST\\_o6/AG03332E07.doc](http://scm.oas.org/doc_public/ENGLISH/HIST_o6/AG03332E07.doc).

## D. Disability and Human Rights - General

- Cojocariu C, *Handicapping Rules: The Overly Restrictive Application of Admissibility Criteria by the European Court of Human Rights to Complaints Concerning Disabled People* (London: Sweet & Maxwell, 2011). <http://www.interights.org/campeanu/index.html>.
- Council of Europe, Commissioner for Human Rights, *Human Rights and Disability: Equal rights for all* (October 20, 2008). <https://wcd.coe.int/ViewDoc.jsp?id=1355349>.



- Ginnerup S, *Achieving full participation through Universal Design*, Adopted by the Committee on the Rehabilitation and Integration of People with disabilities (Council of Europe Publishing, April 2009). [http://www.coe.int/t/dg3/disability/source/Universal\\_design.pdf](http://www.coe.int/t/dg3/disability/source/Universal_design.pdf).
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- Inclusion International, *Hear Our Voices: People with an Intellectual Disability and their Families Speak Out on Poverty and Exclusion* (2006). [http://ii.gmalik.com/pdfs/Hear\\_Our\\_Voices\\_with\\_Covers.pdf](http://ii.gmalik.com/pdfs/Hear_Our_Voices_with_Covers.pdf).
- Pineda V et al., *Ensuring Rights in Development: Implementing the UN Convention on the Rights of Persons with Disabilities with select case studies from the MENA Region* (Open Hands Initiative and Victor Pineda Foundation, 2011). <http://www.openhandsinitiative.org/projectAreas/disabilityGuidebook.html>.
- Quinn G and Degener T et al., *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability* (United Nations, 2002). <http://www.ohchr.org/Documents/Publications/HRDisabilityen.pdf>.
- Quinn G et al, *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities* (European Foundation Centre, October 2010). <http://www.efc.be/Networking/Interest-GroupsAndFora/Disability/Pages/Study.aspx>.
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- Theytaz-Bergman L and Trömel S, *Guidance Document: Effective use of international human rights monitoring mechanisms to protect the rights of persons with disabilities* (International Disability Alliance, May 2010).
- United Nations Department of Economic and Social Affairs (UN-DESA), the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Inter-Parliamentary Union (IPU), *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities: Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities* (2007). <http://www.un.org/disabilities/default.asp?id=212>.
- United Nations General Assembly, Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, A/HRC/10/48 (2009). <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.48.pdf>.
- United Nations General Assembly, Report of the United Nations High Commissioner for Human Rights on progress on the implementation of the recommendations contained in the study on the human rights of persons with disabilities, A/HRC/4/75 (January 2007). <http://www.un.org/disabilities/default.asp?id=135>.
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- Vasquez J, *Human Rights & Health: Persons with Disabilities* (Pan American Health Organization, 2008). [http://www.paho.org/english/dd/pub/10069\\_Disabilities.pdf](http://www.paho.org/english/dd/pub/10069_Disabilities.pdf).
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- WHO and World Bank, *World Report on Disability* (2011). [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf).

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## E. Health Care and Disability

- European Union Agency for Fundamental Rights, *Inequalities and multiple discrimination in access to quality healthcare* (March 2013). <http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare>.
- Human Rights Watch, *Involuntary Treatment: The Invisible Health Care Crisis* (Mar 5, 2013). <http://www.hrw.org/news/2013/03/05/involuntary-treatment-invisible-health-care-crisis>.
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- WHO, “Disability and Health” (2012). <http://www.who.int/mediacentre/factsheets/fs352/en/index.html>.

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## F. Disability and Reproductive and Sexual Health

- Center for Reproductive Rights, *Reproductive Rights and Women with Disabilities: Human Rights Framework* (2002). [http://www.handicap-international.fr/bibliographie-handicap/4PolitiqueHandicap/groupes\\_particuliers/Femmes\\_Genre/reproductive\\_rights.pdf](http://www.handicap-international.fr/bibliographie-handicap/4PolitiqueHandicap/groupes_particuliers/Femmes_Genre/reproductive_rights.pdf).
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## G. Education and Disability

- Human Rights Watch, *Futures Stolen: Barriers to Education for Children with Disabilities in Nepal* (August 2011). <http://www.hrw.org/reports/2011/08/24/futures-stolen>.
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  - The WHO Disability and Rehabilitation newsletter is produced three times a year and distributed via e-mail. Subscription via: [http://www.who.int/violence\\_injury\\_prevention/email\\_signup/en/index.html](http://www.who.int/violence_injury_prevention/email_signup/en/index.html).
  - The latest copy is available via <http://www.who.int/disabilities/publications/newsletter/en/>.

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## Q. Toolkits

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## 6. WHAT ARE THE KEY TERMS RELATED TO DISABILITY AND HUMAN RIGHTS?

### A

#### ***Accessibility***

Accessibility describes the enabling of persons with disabilities to access, on an equal basis as others, the physical environment; transportation; information and communications, including information and communications technologies and systems; and to other facilities and services open or provided to the public, both in urban and rural areas. (CRPD Art. 9)

#### ***Accommodation - Reasonable***

Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. (CRPD Art. 2)

#### ***Assistive Devices; Assistive Technology***

Assistive devices or technology are designed, made or adapted to increase mobility, hearing, vision and communication capacities and enable persons with disabilities participate in society. Products may be specially produced or generally available for people with a disability. (World Health Organization)

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### B

#### **Barriers**

Barriers can take a variety of forms, including those relating to the physical environment or to information and communications technology (ICT), or those resulting from legislation or policy, or from societal attitudes or discrimination. The result is that persons with disabilities do not have equal access to society or services, including education, employment, health care, transportation, political participation or justice.

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### C

#### ***Community living***

Community living is realized when persons with disabilities live in the community and participate in society as equal citizens. The focus of community living is to create an enabling social and physical environment so that all persons are able to be included and participate in a community.

#### ***Community-based services***

These are the range of services and support that enable persons with disabilities to live in the community, participate in community life and to pursue educational and employment opportunities. The range of services include anything required to enable community living and include housing, supported housing, access to mainstream services such as health care, supported employment, day services and care in the family home, social work support, the provision of independent living skills such as teaching on cooking or managing personal finances.

**Communication**

Communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology. (CRPD Art. 2)

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**D****Deinstitutionalization**

This term is used to describe the process of closing or scaling down long-term, residential institutions. Deinstitutionalization should be coupled with the development of community living options in order to be successful by providing alternatives for former residents of institutions.

**Disability**

The Convention on the Rights of Persons with Disabilities (“CRPD”) does not provide a definition of disabilities, but instead provides a broad description intended to be widely inclusive. The CRPD explains in Article 1 that ‘persons with disabilities’ includes ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’. This description of disability shifts the focus towards social and environmental barriers that hinder an individual’s participation in society rather than on the individual’s impairments.

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**E****Education – Inclusive**

Inclusive education focuses on the right of persons with disabilities to participate in the general education system and to not be discriminated against on the basis of disability. Schools must provide reasonable accommodations and the support required to facilitate the effective education of persons with disabilities. (CRPD Art. 24)

**Equalization of Opportunity**

Equality of opportunity is one of the general principles of the CRPD listed in Article 3. It is the “process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.”<sup>101</sup>

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**G****Guardianship**

This term refers to the legal arrangement where the court may deem an individual to lack capacity to make decisions for them self and appoint a person, called the guardian, who the court authorizes to make decisions on the individual’s behalf. Guardianship is also referred to as substituted decision-making. For the human rights-based approach to individual capacity and decision-making, please see “supported decision-making.”

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<sup>101</sup> UN Enable, “World Programme of Action Concerning Disabled Persons.” <http://www.un.org/disabilities/default.asp?id=23>.

## H

### **Health**

Complete physical, mental, and social well-being rather than merely the absence of disease or infirmity. (World Health Organization)

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## I

### **Impairment**

Any loss or abnormality of psychological, physiological or anatomical structure or function.<sup>102</sup>

### **Informed consent**

A process by which a patient makes informed choices about their own health care and provides consent to the provider to carry out that care. The patient must be provided with adequate and understandable information, including on the treatment's purpose, alternative treatments, risks, and side-effects, in order for the consent to be valid. Persons with disabilities have the right to provide or withhold informed consent for any and all medical interventions.

### **Institution**

*An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or congregated and are denied the opportunity to make decisions about their lives or participate in the community as equal citizens. An institution is not defined merely by its size. While an institution may be a large, long-term residence facility, it is any place in which people do not have, or are not allowed to exercise control over their lives and day to day decisions.*

### **Institutionalization**

Institutionalization is used to describe the practice of confining a person with a disability to a residential institution, often against their will, and depriving them of their right to live independently and the ability to make decisions about their lives.

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## L

### **Language**

"Language" includes spoken and signed languages and other forms of non-spoken languages. (CRPD Art. 2)

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## P

### **Personal Assistant**

Persons with disabilities may chose to employ a personal assistant to ensure their independence. Personal assistants are employed by the person with a disability. The person with a disability manages and controls who to hire and fire, and authorizes and manages the type and method of services provided, when services are required, the work schedule, and training of the personal assistant.<sup>103</sup>

<sup>102</sup> UN Enable, "World Programme of Action Concerning Disabled Persons." <http://www.un.org/disabilities/default.asp?id=23>.

<sup>103</sup> Independent Living Institute, "Personal Assistance: Key to Independent Living as Illustrated by the Swedish Personal Assistance Act." <http://www.independentliving.org/node/1193>.

**R****Reasonable accommodation**

See “Accommodation – reasonable”.

**Rehabilitation**

*Rehabilitation* refers to “a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment.”<sup>104</sup>

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**S****Sign Language Interpretation**

A sign-language interpreter is a person trained to interpret information from sign language into speech and vice versa. There are many different sign languages across the world.

**Social Determinants of Health**

Social determinants refer to underlying factors that determines an individual’s health. Social determinants include access to safe and potable water and adequate sanitation; an adequate supply of safe food, nutrition and housing; healthy occupational and environmental conditions; access to health-related education and information, including on sexual and reproductive health; education; availability of social services; and income.

**Substituted decision-making**

See Guardianship.

**Supported decision-making**

Supported decision-making is a decision making approach according to which supporters, advocates or established systems may assist an individual with disability to make his or her own decision or express his or her will, provided the supporter, advocate or system is not in conflict of interest or in a position of power or undue influence over the individual. Supported decision making, as opposed to traditional substitute decision-making or guardianship, does not imply a transfer of decision making rights to third a party.

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**U****Universal Design**

Universal design refers to the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. (CRPD Art. 2)

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<sup>104</sup> UN Enable, “World Programme of Action Concerning Disabled Persons.” <http://www.un.org/disabilities/default.asp?id=23>.