



Protection of the patient's rights

with focus on persons with intellectual disability

In the preparation of the brochure, also participated:

Republic Centre for Support of Persons with Intellectual Disability - PORAKA



Republic Centre for Support of Persons
with Intellectual Disability - PORAKA
www.poraka.org.mk



Association for emancipation, solidarity and
equality of women of R. of Macedonia
Street Maxim Gorki 20/1-4
1000 Skopje
Republic of Macedonia
phone: ++389 (0) 2 3298 295
fax: ++389 (0) 2 3211 453

esem@esem.org.mk
www.esem.org.mk



The brochure is part of the project:
Human rights in health care

The Right to health is a universally recognized right. The World Health Organization defines this right for the first time as a “right of every person to the highest attainable standard of physical and mental health”.

The right to health is closely related to the protection of the rights of patients, which represent a set of rights, responsibilities and duties according to which the patients request and receive health care.

In Republic of Macedonia, these rights are provided for in the Law on Protection of Patients’ Rights.

Patients' rights

Right to preventive measures

Preventive measures consist of activities that prevent a disease or a condition; or to alleviate consequences of diseases.

The causes for intellectual disabilities are multiple and complex (hereditary, congenital, social) and thus it is difficult to single out only one factor for their etiology. If we understand the consequences of intellectual disabilities on the life of an individual, their family and the community, the necessity of a wide range of preventive measures is obvious. These measures are still limited in Macedonia.

Example:

The health care system in Macedonia offers access to:

PRISCA- (Prenatal Risk Calculation) is a noninvasive biochemical screening of chromosomal diseases that does not have a diagnostic value, but calculates risk of occurrence of malformations leading to occurrence of congenital intellectual disability of a newborn.

Amniocentesis- a medical procedure used in prenatal diagnosis of chromosomal abnormalities in the genetic karyotype of the fetus. This technique used in early pregnancy can identify fetal chromosomal aberrations, which confirm occurrence of intellectual disability (e.g. Dawn's Syndrome).

Right to access

Every patient has a right to health care without discrimination based on gender, race, language, faith, political or any other affiliation, national origin or social standing, national minority, financial standing, birth origin, sexual orientation or any other status.

Intellectual disability has not been listed as a basis for discrimination, however the provisions of this Law refer also to persons with intellectual disability as users of health care services that are entitled to unobstructed access to regular and specialized health care services and programs, suitable for their needs.

Example:

The right to access of the persons with intellectual disability is not exercised accordingly, because of:

Lack of specialized health care services, programs and service providers for prevention, early detection, diagnosing, early treatment and rehabilitation of children and persons with intellectual disability in Republic of Macedonia;

Certain age group of people with intellectual disability faces limited access to provision of free health care, treatment and medicines. The Law on Health Insurance provides for free health care only for children, i.e. people with intellectual disability up to 26 years of age, but not for people above that age.

People with disabilities face various challenges when they purchase necessary medication: the medicines are often expensive, or are not found on the positive list, or if they are, they are unavailable. The reimbursement procedure for the cost of the medicine is lengthy.



Right to information

The patient has a right to complete information about: his health condition, including medical assessment of the results and outcome of medical interventions; recommended medical interventions and proposed dates; potential risks and expected benefits, his right to decide on the recommended interventions; substitutes for the recommended medical interventions; reasons for any differences in outcome and the estimated outcome; the entire procedure of provision of health care; recommended lifestyle changes and rights to health care and health insurance, as well as the procedure for exercising those rights.

All information has to be provided to the patient in a suitable manner, making sure the patient understands all information and avoiding all technical, i.e. medical terminology in order for the patient to understand the important information for his/her treatment.

Patients with permanently reduced ability for reasoning also have a right to information, in accordance with their physical, mental and psychological condition. This right also extends to their guardian or legal representative.

Example:

People with intellectual disability have difficulty understanding medical terminology. The parent or guardian usually receive the information, therefore they need to be present during the entire medical intervention or treatment. As a result, communication between a person with intellectual disability as a patient and the medical staff providing health care is usually challenging.

When a child with intellectual disability over 3 years of age uses hospital care, the law does not provide for the guardian to be present with the child free of charge. This situation limits the communication between the patient with intellectual disability and the medical staff, as an important condition for effective health care and treatment.

Right to consent

Every patient has the right to accept or decline certain medical intervention by signing a statement. The right of the patient for participation in the decision making process may be limited only by exception, if it is justified with the health status of the patient.

The parent, guardian or legal representative signs the statement for the person with intellectual disability who are not able to represent themselves, as well as for those without working ability.

In case when the interests of the patient and his parent, legal representative, or guardian are opposing, the health institution is responsible to report to the Center for social work, responsible for resolving the dispute in order to protect the patients' interests.

Example:

Persons with intellectual disability are very rarely consulted and included in the process of decision making because of the lack of mechanisms that would confirm that the person with intellectual disability has been given support in order to understand the health status and to make a decision for a certain medical intervention.

Right to respect of personality and dignity

Health care workers should treat all patients with respect and all patients should have equal treatment, without discrimination on any basis. The health care worker has to establish humane relation with the patient with intellectual disability.

Example:

Due to lack of information and unawareness of the characteristics of an intellectual disability, as well as existing prejudices, persons with intellectual disability and their parents usually face inappropriate treatment from health providers and they receive substandard health care.

Additionally, use of inadequate terminology also contributes to increase of prejudices that persons with intellectual disability face, as they are treated as mentally ill persons.

Rights to respect of the quality standards

Right to respect of the quality standards means that every patient has a right to health care that enables best results in prevention/treatment, according available professional and technical achievements in medicine. In practice, that means that the latest available medical methods and medical materials should be used, medicines manufactured according strict standards, etc. in accordance with the protocols stipulated on basis of evidence- based medicine.

Example:

Estimation of specific needs (categorization) of persons with intellectual disability, according the Guidelines for estimation of specific needs of people with intellectual disability in physical and psychological development, is carried out in several regional Committees, which employ an outdated medical model and approach to people with intellectual disability. In fact, the estimation is focused on the limitations of the person with intellectual disability, and not the estimation of the potential of the individual with an option for recommendation for inclusion in certain developmental programs for development of the individual's capacity.

Right to prevention from unnecessary suffering and pain

In medicine there are procedures for diagnosing and treatment, which unfortunately cause pain and inconveniences. Often, diseases themselves are painful.

It is a tendency in medicine to strive to alleviate patients' pain as much as possible in order to avoid unnecessary suffering.

Example:

Most people with intellectual disability are afraid to visit doctors, especially dentists, which is the reason why these people have poor dental health.

Several dentists/oral surgeons in Republic of Macedonia are ready to perform interventions under general anesthesia, in order to reduce pain and successfully complete the planned operation.

Right to access of a medical file

The patient can have access to his/her medical file and receive a copy of the documents in the file, or s/he can appoint another person on his/her behalf to access the file, as well as to acquire more information regarding the information in the medical file.

Apart from the medical staff, no one else is allowed to access the medical file of the patient without his/her consent.

Right to contact

The patients can admit visitors in accordance with the house rules of the health care provider, and the visits can be limited to one or several persons.

Example:

Within their competencies, the public and private health care institutions provide access to the media (TV, radio, daily newspapers and magazines) and a telephone (at additional cost) for their patients.

Right to second professional opinion and consultation

The patient may always request second professional opinion for his health issues from a health care provider with at least equal level of expertise, but who hasn't participated in the initial medical intervention of the patient.

Right to personalized treatment

Each patient has a right to health care, treatment and rehabilitation which are in accordance with his individual needs and abilities. Health care workers should make the most to adapt medical interventions to the specific needs of patients.

Example:

The right to personalized treatment is especially important for the persons with intellectual disability. Their parents, guardians, legal representatives and themselves need to inform the health care worker about the history of the disease and the specifics of the disability, as well as the medical interventions that had been done previously, so that the treatment is suitable to the needs and characteristics of the patient.

Right to complaint

If a certain right is being violated, the patient has a right to oral complaint, personally, through the parent, or his/her legal representative, to the director of the health care institution.

The patient has also a right to submit written complaint to the director of the health care institution within eight days of the day of the violating of the rights or from the acknowledgement that a right has been violated, and the director is required to investigate the allegations made in the complaint within 15 days of the day of the receipt of the document and let the patient or his legal representative know the outcome.

Example:

The patient sends a written complaint to the director of the health care institution regarding the attitude of the medical worker. The director, after reviewing the allegations, points out the mistake to the medical worker and it is corrected within the institution.

Right to access new procedures for treatment and diagnostics

Health institutions are obliged to provide the patient with the highest possible personal level of health care, in accordance with the available methods and achievement of the medicine, through use of new and modern interventions and treatments. If certain health care institution is not available in the country, the patient should be given the opportunity to receive treatment abroad.

Example:

Republic of Macedonia lacks new specialized health care services (programs and services for prevention, early detection, diagnostics, early treatment and rehabilitation of children and persons with intellectual disabilities) which are daily, routine practice in the countries of the region.

Right to treatments on time

Respect of the time of the patient means that every patient has a right to use health care according the level of emergency according medical criteria, i.e. the nature of the disease.

In case there are waiting lists for a certain consultation or operation, the selection and order of check-up/treatment/operation have to follow strictly medical criteria, without discrimination on any basis.

Right to confidentiality and privacy

Every patient has a right to confidentiality (secrecy) of personal and medical data, which have to be kept secret even after the death of the patient, in accordance with the regulation for protection of personal data, except when the patient has given written consent; when the data is needed for a medical intervention of the patient in another institution; when the data is necessary for processing as required by law, by the health care provider that provides health care services for the patient; and when they are used in historical, scientific, research or educational purposes, for animal protection, security or health of other persons, provided that the identity of the patient remains confidential.

The right to privacy also ensures that during a stay in a health care institution the patient is accommodated with persons of the same gender, and if the patient is a minor, s/he should be accommodated separately from adult patients. The patients have the right to use personal hygiene items and other necessary items in accordance with their health condition.



PATIENTS' OBLIGATIONS

Each patient, during their stay in the health institution is required, in accordance with their health condition, to:

1. take care of their own health;
2. give truthful and sufficient data for his/her health condition, according personal capacity and available information ;
3. help health care givers who provide health care;
4. act according the advice from the health care givers for his/her care, treatment and rehabilitation;
5. respect the code of conduct, i.e. house rules in the health care institution;
6. accept engagement, if it is part of his/her rehabilitation and resocialization in order to reactivate their social skills and
7. respect professional and human dignity of the health care givers.



WHERE CAN YOU LOOK FOR HELP IN CASE YOUR RIGHTS HAVE BEEN LIMITED OR VIOLATED?

If you think that a certain right has been limited or violated in any of the public hospitals (hospital, clinic, institution) check if there is a counselor for protection of the rights of patients in that hospital. The counselor can give you legal advice or can help you submit oral/written complaint. If the hospital doesn't have a counselor or the violation took place in non-hospital health care institution (health station) the complaint is to be submitted directly to the director of that institution.

The director of the institution, once s/he investigates the allegations made in the complaint, is required to report on the measures undertaken within 15 days.

If you think that the director has not undertaken the necessary measures, you can submit a complaint to the Ministry of Health, which is required to investigate allegations made in the complaint within 15 days, and to report back on the measures taken.

At the same time, you can submit a request for inspection also to the State sanitary and health inspectorate, which have the power to order the health care institution and the health worker to undertake measures and activities depending on the type of violation.

Within the municipalities, Committees for improvement and protection of the rights of the patients have been established. You can also submit a complaint to this Committee, and they are required to review the complaint and to redirect you to competent authorities in order to help you exercise your rights.

If you aren't content with any of the responses from the above mentioned bodies, you can initiate proceedings before a competent court.

If your right in the field of health insurance has been violated, request assistance in the Health Insurance Fund of Republic of Macedonia and its branch offices.

CONTACT

?



WHO CAN HELP YOU EXERCISE YOUR RIGHTS?

Republic Centre for Support of Persons with Intellectual Disability - PORAKA
Str. "Orce Nikolov" No.122, 1000 Skopje
Tel: 02/3296-961 Fax: 02/3296-960

Centre for support of persons with intellectual disability - PORAKA, Skopje
Str. "Jane Sandanski" No.70 shop 1, 1000 Skopje, tel: 02/2451-008

Centre for support of persons with intellectual disability - PORAKA, Tetovo
Str. "180" No.19/9, 1220 Tetovo, tel:075/258-979

Centre for support of persons with intellectual disability - PORAKA, Kumanovo
Str. "Zivko Calo" No.41, 1300 Kumanovo, tel: 071/353-570

Centre for support of persons with intellectual disability - PORAKA, Bitola
Str. "Dame Gruev" No.99, 7000 Bitola, tel: 071/368-402

Centre for support of persons with intellectual disability - PORAKA, Prilep
Str. "Stevan Apostolski" room No.5, 7500 Prilep, tel: 048/410-393

Centre for support of persons with intellectual disability - PORAKA, Demir Hisar
Str. "29th November" No.15, 7240 Demir Hisar, tel: 070/373-589

Centre for support of persons with intellectual disability - PORAKA, Kavadarci
Municipal building, 1430 Kavadarci, tel:043/411-773

Centre for support of persons with intellectual disability - PORAKA, Gevgelija
Str. "Marsal Tito", 1480 Gevgelija, tel: 034/211-993

Centre for support of persons with intellectual disability - PORAKA, Veles
Str. "Blagoj Gjorev" No.70/10, 1400 Veles, tel: 071/315-220

Centre for support of persons with intellectual disability - PORAKA, Vinica
Str. "Pirinska" No.22, 2310 Vinica, tel: 072/211-549

Centre for support of persons with intellectual disability - PORAKA, Strumica
Str. "Krusevska Republika", No.22, 2400 Strumica, tel: 071/311-804

Centre for support of persons with intellectual disability - PORAKA, Debar
Str. "Liman Kaba" No.3, 1250 Debar, tel: 070/468-944

Centre for support of persons with intellectual disability - PORAKA, Kriva Palanka
Str. "Jane Sandanski" No.30, 1330 Kriva Palanka, tel: 071/267-263

Centre for support of persons with intellectual disability - PORAKA, Delcevo
Str. "Ostrec" No.76, 2320 Delcevo, tel: 071/707-885

Centre for support of persons with intellectual disability - PORAKA, Radovis
Str."Spaso Radovski", 2420 Radovis, tel: 032/635-826

Centre for support of persons with intellectual disability - PORAKA, Stip
Str. "Sutjeska", 2000 Stip, tel: 032/608-216

Centre for support of persons with intellectual disability - PORAKA, Makedonska Kamenica
Str. "Kamenicka", Municipal building, 2304 Makedonska Kamenica,
tel: 071/856-039

Health Institutions

Centre for monitoring growth and development of children born with risk
Str."Krste Misirkov" Skopje
02/3134-534, ext.409
02/3134-661

Child and Adolescent Mental Health Care Institution "Mladost"
Str. "Partizanski Odredi" No.60a, 1000 Skopje
02/3065-711
02/3068-307
02/3061-509

Institute of Physical Medicine and Rehabilitation
Str. "Elisie Popovski" No.28, Skopje
02/3176-584

Institute for rehabilitation of hearing, speech and voice - Skopje
Str. "Belgradska" No.15, Skopje
02/3239-226

Institute for rehabilitation of hearing, speech and voice - Bitola
Str. "Elpida Karamandi" No.28, Bitola
047/224 479



ESEM

Association for emancipation, solidarity and
equality of women of R. of Macedonia
Street Maxim Gorki 20/1-4

1000 Skopje

Republic of Macedonia

phone: ++389 (0) 2 3298 295

fax: ++389 (0) 2 3211 453

esem@esem.org.mk

www.esem.org.mk



The brochure is part of the project:
Human rights in health care

ЧОВЕКОВИТЕ ПРАВА

во здравствената заштита
ПРИРАЧНИК ЗА ПРАКТИЧАРИ

МАКЕДОНИЈА



*the electronic version of the manual can be
downloaded on our website:
www.healthrights.mk

BECOME FAMILIAR WITH:

- Basics of human rights in health care through the Manual on human rights in health care
- International and regional documents and mechanisms that guarantee and protect the implementation of the right to health
- National legislation and ways to protect the right to health in our country
- Rights and obligations of health workers in provision of health care
- Rights and obligations of patients in the realization of health care and health insurance
- Relevant publications that refer to different health matters and access to health care
- Institutions that work in the sphere of health care, health insurance and legal protection provision in our country