



**Association for Emancipation, Solidarity and Equality of Women in Republic of Macedonia**

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## **WOMEN'S HEALTH**

## **MONITORING AND ANALYSIS OF THE PROGRAMME FOR EARLY DETECTION OF MALIGNANT DISEASES (CERVICAL CANCER AND BREAST CANCER)**

During 2013, ESE continued its work in the area of monitoring and analysis of budgets in order to expand the scope of women with measures for early detection and treatment of breast cancer and cervix cancer.

During the period February- March 2013, we completed the mapping of health care institutions and institutions that participate in the implementation of the Programme, as well as mapping of the system and financing of this Programme. Based on the map, we monitored the operations of the following institutions: Ministry of Health; Health Insurance Fund; all participants in the Programme (public institutions at primary, secondary and tertiary level), the Ministry of Finance; the State Audit Office; as well as the parliamentary committees for finances and budget and health care system. We also carried out activities for advocacy aiming at improvement of the transparency and accountability of their operations.

After the process of mapping, we started gathering relevant data for realization of the activities of the Programme. Data collection was done through: analysis of publicly available documents, requests for access to public information, document review and meetings with authorized persons. The following publicly available documents were analyzed: Guidelines for the operations of the treasury, Law on accounting in budgets and budgetary users, Law on budgets, Programmes for active health care protection of mothers and children for 2012 published in the Official Journal, Guidelines and rulebooks for treasury operations of institution of the central government and the Health Insurance Fund of Republic of Macedonia.

Based on the information acquired from the publicly available documents, as well as the previous experience of ESE in this field, we developed a strategy, through which we requested copies of the documents for programme and financial operations, from every participant in the Programme. The objective of this approach was to collect data from various sources that we can compare in order to determine the significance of the data given in the documents prepared by diverse participants.

Apart from data requests, during the process for accessing publicly available data, we contacted representatives of several institutions personally or via telephone, from the following institutions: Sector for preventive health care at the Ministry of Health, Centre for Public Health, Skopje, Centre for Public Health Kumanovo, General Hospital Prilep, etc.

These contacts were instrumental for acquiring information regarding the documents that the institutions have at disposal, to determine which documents do not exist in the requested format and/or for the potential source for acquiring the requested documents. Apart from that, they also informed us about the challenges they face in the process of performing the activities for the Programme. The following were identified as major challenges:

Irregular payments or non-payment of the funds as per submitted invoice by the Ministry of Health; difficulties in conducting activities because of lack of sufficient materials and staff; Lack of unified health care records and statistics; lack of information for certain obligations they have according the Programme, etc.

The next step was to process the acquired data, i.e. we compared the planned and the completed activities and budgets and compared the data that we received from institutions at various levels of Programme implementation.

After we analysed the data, we prepared a document that presented the findings of the analysis of the program and budget implementation of the two programme components of the Programme for early detection of malignant diseases for 2012 (cervix cancer and breast cancer), i.e. we identified irregularities in planning of the programme and differences in the narrative and the financial part of the Programme; lack of data for implementation of the screening; differences in data that refer to the program and budget implementation of the Programme which have been prepared by different program implementer; unsuitable coordination between the implementers of the screening have been identified; a single register of the screening doesn't exist. Apart from that, the screening methodology for early cervix cancer detection is not completely harmonized with the recommendations from the World Health Organization.

In order to strengthen the advocacy process and increase the quality of the claims we use in the analysis of the Programme for early detection of malignant diseases, we also prepared an analysis of the organization of the health care network for primary health care and geographical distribution of primary care gynaecologists in Republic of Macedonia; we identified the number of women who have selected a primary care gynaecologist and analysed the funds that the Health Insurance Fund pays the primary care gynaecologists in form of capitation.

We identified that there is an inappropriate and insufficient number of women in R. Macedonia who have a primary care gynaecologist.

The monitoring and analysis of the implementation of the Programme for early detection of malignant diseases produced the following results:

- Increased number of target institutions for monitoring and advocacy of 1 (one) in 2012 (Ministry of Health) of the following institutions: all implementers in the programme for early detection of malignant diseases (Public Health Care Institute, Public Health Centres, general and clinical hospitals, university clinics, health care organizations); the Health Care Fund; Ministry of Finance and the State Audit Office;
- Analysed publicly available documents that are relevant for the operations of the monitoring field, among which: The Programme for early detection of malignant diseases published in the Official Journal, Guidelines for the work of the treasury, Law on accounting and budget users, Law on budgets, guidelines for treasury work in the institutions of the central government and the Health Insurance Fund of Macedonia;
- Direct meetings with the authorities from 4 (four) relevant institutions; Ministry of Health, Public Health Centre Skopje, Centre for public health Kumanovo and the general hospital in Prilep;
- Mapping of the key sectors and officials in the Ministry of Finance carried out;
- Completed mapping of the key sectors and officials at the Health Insurance Fund in Macedonia
- Identification and review of the available documents that are issued by the State Audit Office;

- Conducted monitoring and analysis of the program and budget implementation of the Programme for early detection of malignant diseases and prepared detailed reports;
- Total cost analysis of the costs in health care in R. Macedonia prepared;
- Financial/budget operations analysis of HIFM prepared;
- Data from final audit reports processed and identified information that could be used for advocacy;
- Established cooperation with the president of the Committee for financing and budget in Parliament of Republic of Macedonia.

### ***MONITORING AND ANALYSIS OF THE ORIO GRANT IMPLEMENTATION***

Apart from the regular monitoring and analysis of the preventive programmes, in 2013, ESE started activities for monitoring and analysis of the implementation of the development phase of the ORIO Grant that the Ministry of Health received from the Government of Netherlands, which is to be used for infrastructural development and promotion of mother and child health. The extension of monitoring of this Grant shall contribute to promotion of the quality of the claims and strengthening of the process of advocacy for an increased scope of the Roma children with vaccination and preventive health care services, above all, the health visiting services. It is significant to mention that the Ministry of Health with the budget of the Programme for active health care of mothers and children secures co-funding of the activities of this Grant. For this purpose we received requests for access to public information to the Agency for managing with ORIO, Netherlands and the Ministry of Health. During the reporting period we received responses from both parties, and then we processed the information and included findings in the analysis of the Programme for active health care protection of mothers and children.

## ROMA HEALTH

## **MONITORING AND ANALYSIS OF THE PROGRAMME FOR ACTIVE HEALTH CARE OF MOTHERS AND CHILDREN**

During 2013, ESE continued working in the field of monitoring and analysis of budgets and monitoring of the community, aiming at increasing the scope of Roma children to receive mandatory vaccination and preventive health care services.

During the procedure for monitoring and analysis and the budget implementation of the Programme for active health care of mothers and children, we used the following methods and techniques for providing relevant data: **mapping and analysis of public documents; carrying out procedure for access to public information; and monitoring in the community**, through offering technical support of the Roma civil association that performs this methodology in the field.

Although methods and techniques are similar of the ones used in the previous years, ESE made significant changes in their use this year, aiming at overcoming the identified drawbacks and challenges. We extended the number of target institutions; we started a number of activities in order to improve transparency of public institutions. We also changed the methods of information discovery, thus instead of information, this year we request documents supporting institutions' statements.

The procedure of access to public data is also conducted using all mechanisms for protection and insuring the access to the public information. We started a new process for research in the community, and initiated preparatory activities for including a component for social revision in the current operation in the fields of monitoring of the community. The activities we conducted in the field of monitoring and analysis of budgets and monitoring of the community, were continuously accompanied with measures for advocacy to the target institutions.

During the period February- March 2013, we mapped health care institutions and organizations included in the Programme, as well as mapping of the funding system of this Programme. We did this with the goal to determine institutions and the authorized persons included in the realization of the preventive activities, consisted in the Programme.

Based on the prepared map, during 2013 we monitored the operations of the following institutions: Ministry of Health; Institute for health care of mothers and children; Health Insurance Fund of RM; Ministry of Finance; State Audit Office and the parliamentary committees for finance, budget and health. We also conducted activities for advocacy in these institutions, aiming at promotion of transparency and accountability of their work.

After mapping the relevant institutions, we collected data for realization of the activities and funds of the Programme, through the standard procedures for data collection that ESE uses. We analysed the following public documents: Guidelines for the operations of the treasury, Law on accountability and budget users, Law on budgets, Programme for active health care of mothers and children for 2012 published in the Official Journal, Guidelines and documents for regulating the work of the health visiting services and treasury operations of the institutions of the central government and the HIFM.



For monitoring of this Programme, we also requested copies of documents for the programme and financial operations, which each of the implementers in required to submit for the Programme.

The goal of this approach was to secure data from several sources that we can compare in order to determine the value of data presented in the documents prepared from various implementers.

Apart from submitting of the requests, during the procedure for access to public data, we also met or talked to representatives of the following institutions: Sector for preventive health care at the Ministry of Health, Health Centre Skopje, Health Centre Strumica and Health Center Ohrid. Through these contacts, we acquired information on the documents these institutions have, which documents are not available in the requested format and/or the potential source for acquiring the requested documents.

They informed us about the problems they are facing during the Programme.

Irregular payments or non-payment of the funds as per submitted invoice by the Ministry of Health; difficulties in conducting activities because of lack of sufficient materials and staff; Lack of unified health care records and statistics; lack of information for certain obligations they have according the Programme, etc.

The next step was to process the acquired data, i.e. we compared the planned with the completed activities and budgets as planned with the Programme.

The data analysis was used to prepare a document for programme and budget implementation of the Programme for active health care of mothers and children in 2012. This document is in its final phase, and its contents shall be upgraded with the results that shall be acquired from the process of research in the community and social revision, conducted by the partner organizations in this period. Based on the findings of both processes, in the upcoming period we shall initiate a process of preparation of a strategic plan for advocacy at a national level, together with our partner organization, and then we will enforce it.

Through the conduct of the activities for monitoring and analysis of the programme and financial realization of the Programme for active health care of mothers and children for 2012, we accomplished the following results:

- Extended the number of target institutions for monitoring and advocacy from two (2) in 2012 (Ministry of Health and the Institution of health care of mothers and children) to the following institutions: all implementers of the Programme for active health care of mothers and children (Health Care Centres); Health Insurance Fund; Ministry of Finances and the State Audit Office.
- Analysed public documents relevant for the operations in the field of monitoring, among which: Programme for active health care of mothers and children for 2012 published in the Official Journal, Guidelines for the treasury operations, Law on accounting and budget users, Law on budgets, guidelines and documents for regulating the work of the health visit services and the treasury operations of the central government and the HIFM;
- Direct meetings with the authorities from 4 (four) relevant institutions; Ministry of Health, Public Health Centre Skopje, Centre for public health Strumica and the general

hospital in Ohrid, which are competent for enforcing the Programme for active health care of mothers and children in 2012;

- Mapped key sectors and personnel at the Ministry of Finance;
- Mapped key sectors and personnel at the Health Insurance Fund of RM
- Identified and reviewed documents issued by the State Audit Office;
- Conducted process for monitoring and analysis of the programme and budget implementation of the Programme for active health care for mother and children and prepared reports;
- Total cost analysis in health care in R. Macedonia;
- Analysis of the financial/budget operations of HIFM;
- Processed data contained in the final audit reports and determined data that could be used for advocacy;
- Started monitoring and implementation of the development phase of the ORIO Grant;
- Established cooperation with the president of the Committee for financing and budget in the Parliament of R. Macedonia.

## COMMUNITY MONITORING

In 2013, ESE continued to secure technical assistance and coordination of the four partner organizations regarding activities of the monitoring of the community on a local level, as well as the activities that are carried out on a national level. Technical assistance and coordinative activities consist of: activities for capacity building of the civic partner organizations; organization of informative and coordinative meetings regarding exchange of information and experiences of conducting the process of joint planning of the future activities; establishing communication among the civic organizations and the external associates engaged for promotion of the process of monitoring of the community; establishing a system for continuous information exchange; supervising and monitoring of the implementation process; technical assistance for preparation of various materials by the organizations included in the process; technical assistance for preparation of the working methodologies; coordination of the process of planning of the activities for advocacy and the process of advocacy and strengthening of the capacities of partner organizations.

The following activities were carried out in 2013:

- **Development of a national strategy for advocacy and local strategies for advocacy.** National strategy for advocacy for 2013 was developed by all partner organizations in a process coordinated by ESE. During the development of the national strategy for advocacy, goals and activities for advocacy that were identified in 2012 have been taken into account, as well as the findings of the monitoring in the community and the monitoring of the Programme on a national level. In accordance with the developed strategy during 2013, the association ESE, and its partner organizations conducted a number of activities for advocacy to the competent authorities, including: submitting draft measures for increased scope of Roma children for vaccination and preventive health care services to the working group for revision of the Programme for active health care of mothers and children supported by the World Health Organization and the Ministry of Health.

For this purpose, the working group received a request with concrete measures based on the findings of the conducted budget monitoring and monitoring of the community. We met with the following members of the working group: Prof. Elena Kjosevska, PhD from the Public Health Institute, Nermina Fakovic and Senad Memedi of the Ministry of Health. We provided support from the working group and all proposed measures were accepted and were included in the Programme for 2014. We met with Ibraim Ibraimi, Deputy Minister at the Ministry of Labour and Social Policy. The main objective of the meeting was securing support and finding ways to improve the process of delivery of invitations for vaccinations to the Roma community. The Deputy Minister expressed his regrets for the problems and he said that he will arrange for Roma carriers to be employed, through the redistribution of the candidates that have been employed through the ad from the vulnerable categories, in the state owned company Macedonian Forests. The Deputy Minister was then presented with the concrete requests that the organizations submitted to the Ministry of Health, also with the aim for their inclusion in the Programme for active health care of the mothers and children for 2014. Deputy Minister pledged his support of the measures in the Ministry of Health. Activities for media advocacy were also conducted. Partner organizations established a group for media advocacy. The group is operating with a technical support by the ESE.

On the occasion of the European Immunization Week (22- 27 April) the group for media advocacy prepared an announcement for the media that was submitted to 23 media outlets and published on 2 internet portals. On 7 November 2013, a press conference was held, for the presentation of the most significant monitoring findings.

- **Preparatory activities for conducting research in the community.**

ESE and partner organizations started preparatory activities for conducting a second process of community research regarding the extension of scope of Roma children with vaccination and preventive health services. Partner organizations also agreed that this cycle of research, apart from children from 0- 5 years of age, shall include also children from 6- 15 years of age. This extension of the research is in accordance with the ESE plan to extend the monitoring on a national level and the Programme for systematic examinations of students and pupils. For the purposes of the research, we prepared questionnaires (for each target group). Questionnaires were also prepared for health care workers. Following the preparations, the partner organizations started conducting field research.

**Analysis of the potential to extend the application of the monitoring methodology in the community to other fields that ESE is working on.**

During 2013, ESE and partner organization agreed to extend the scope, through: inclusion of the methodology of social revision in the current work in the field of immunization of Roma children;

Extending the work in the field of monitoring in the community and social revision of the question for inclusion of Roma women in preventive gynaecological services, especially prevention services for early detection of cervix cancer.

In 2013, we finalized the preparatory activities for initiating the process of social revision in the field of immunization of Roma children, i.e. revision of the reports and working journals of the health visit nurses in the Roma communities. For this purpose, ESE prepared requests for access to public data, for the requested documents (journals and nurses' reports). The same requests were submitted by partner organizations.

Through the activities for monitoring in the community during 2013, the following results were achieved:

- Developed strategies for local advocacies by the four partner Roma civic organizations with ESE technical assistance;
- Developed and conducted national strategy for advocacy by all partner organization with coordination by ESE;
- Inclusion of the proposed measures for extended inclusion of Roma children for vaccination and preventive health care services (planned for in the strategy for advocacy) in the draft Programme for active health care of mothers and children for 2014, prepared by the working group that is working on the revision of the Programme, in a process supported by the WHO and the Ministry of Health;
- Increased number of activities for health education of Roma families for vaccination and children's health from 6 in 2013 to 5.000 families in 2014, in the Programme for active health care of mothers and children in RM for 2014, adopted by the Government of RM.
- Increased amount of allocated funds for educational activities in Roma environment from 30.000,00 MKD in 2013, to 250.000,00 in 2014, in the Programme for active health care of mothers and children in RM for 2014, adopted by the Government of RM.
- Prepared draft projects by three partner Roma civic organizations for their work during the period July 2013- June 2014, with technical assistance from ESE; and
- Conducted activities for media advocacy by the personnel of ESE and partner Roma civic organization with technical assistance by ESE.
- Prepared methodology for conducting of research in the community for extension of Roma children into vaccination and preventive health care services, for children from 0- 5, and from 6- 15 years of age.
- Prepared tools (5 questionnaires) for conducting the research in the community for children from 0- 5 years of age;
- Developed tools (3 questionnaires) for conducting of research in the community for extension of Roma children with vaccination and preventive health care services, for children from 6- 15 years of age.
- Prepared preliminary plan for extension of the applied methodology for community monitoring, through inclusion of the methodology of social revision and extension in the field of work regarding inclusion of Roma women in preventive gynaecological services.

## **BASELINE RESEARCH OF HEALTH CARE STATUS AND HEALTH PROTECTION RIGHTS OF ROMA IN MACEDONIA**

The necessity of preparing a baseline study for the health status of the Roma population, the health care factors, and the access to health care, the respect of human rights in health care and harmonization of the domestic legislation with the international standards for compliance and enforcement of health rights, emerged from the lack of these relevant data. The baseline study is based on data acquired through: conducted field research of sample of Roma population and population from other ethnic groups who live near the Roma population; as well as through analysis of available relevant documents.

In the initial phase of conducting the project, ESE identified external experts that shall take part in the preparation and realization of the research and the development of the final study, i.e. as external experts, Prof. Elena Kjosevska, PhD, and Ass. Blasko Kasapinov, PhD were identified.

In order to collect the required data as planned with the field research, a structural questionnaire was designed, while for the needs of the discussions in the focus groups, a partially structured questionnaire (a guide) was prepared. For the needs of the field research a sample of candidates was selected, conducted by an external associate- Prof. Anica Dragovic, PhD, demographer from the Faculty of Philosophy in Skopje.

Additionally, 18 pollsters were identified and selected. Part of them were identified by the Roma civic organizations, and part by the doctors employed in the Institute for Public Health and the Public Health Centres. In order for the pollsters to become familiar with the methodology and the way of conducting the field research, the method of selection of the sample as well as the questionnaire according which the research shall be conducted, ESE organized a training (instruction) for the pollsters.

After the training, the pollsters conducted the field research among the Roma and the population of the other ethnic groups according previously prepared sample in 10 municipalities in R. Macedonia where most of the Roma live. Discussions in focus groups were also conducted with Roma population and population of the other ethnic groups who live near the Roma neighbourhoods, i.e. in the municipalities of Suto Orizari and Delcevo. Discussions with health care providers who work in Delcevo was also conducted.

Collected data were input and statistically analysed in a statistical application Epi Info. Statistical processing was done in order to compare data between Roma and the other populations. Transcripts were made from the audio recordings. The statements of the interviewees were used for illustration of certain situations through citing in the final report of the study.

For the purposes of the research, we analysed a number of publicly available relevant documents, including: Constitution of RM, laws and bylaws, strategies, programmes, international documents and other secondary sources (analyses, reports, etc.). The analysis that is a result of this process aimed to emphasize the need of harmonization with the international standards for human rights, i.e. the standards regarding exercising and enforcing health care rights guaranteed by international instruments, as well as the necessity of enforcement of health rights measured by relevant indicators.

The Final report of the study contains findings structured in the following way:

- International and regional legal framework for protection of the right to health
- Constitutional and legal framework
- Health care strategy 2020 and action plans for the health care in RM
- Citizen inclusion during development and conduct of health care policy
- Health care financing
- Public budget funds for health care secured by external sources
- Socio- economic factors as social conditions of health
- Health status
- Health care protection
- Patients' rights
- Access to medications
- Access to health care services for women's health
- Discrimination

The following results were achieved in 2013:

- Completed analysis for the conditions regarding health care, right to health and access to health care services among Roma, compared with the conditions of the population of other ethnicities
- Analysis of relevant documents in order to stress the necessity of harmonization of the international human rights standards, i.e. the standards regarding exercise of health rights guaranteed with international instruments, as well as the need of applying of health rights measured with relevant indicators
- Final report that includes findings acquired after the analysis of data of field research
- Study including both previously conducted analyses, which offer integrated insight into the conditions regarding health, access to health care and exercising the right to health for the Roma population in RM.

## **RIGHT TO HEALTH AND PROTECTION OF PATIENTS' RIGHTS**

## HUMAN RIGHTS IN HEALTH CARE

During 2013, ESE continued with realization of the initiated activities for promoting the concept of Human rights in health care, and utilizing new approaches for enforcing the right to health and rights of patients, with renewed focus of activities for advocacy of rights of patients from the marginalized groups.

**Continued updating the content of the Guidelines for practitioners “Human rights in health care”.** The process of continuous updating of the content of the guidelines represents regular and an organized process of monitoring of the national legal framework, integrating of the changes and modifications of the positive regulations which are used and cited in the guidelines, in order to familiarize the practitioners (health care providers, associates, lawyers, judges, managers of health care institutions, representatives of the civic organizations) with the novelties regarding health care, in a timely manner. The process of continuous update of the content in the guidelines and level of familiarization of the practitioners is one of the main activities that contributes to the use of the legal opportunities for protection of the right to health and protection of patient rights by the practitioners. During 2013, the identified news were incorporated in a previously defined monitoring matrix. Input in the said matrix takes place quarterly. ESE was working on publishing of an electronic issue of the Guidelines (from PDF format into Word format) that is to integrate all identified changes and additions in the content of the Guidelines.

### **Preparation of a Brochure for patient rights with a focus on persons with intellectual disability**

Apart from the previously prepared brochures for patients’ rights with focus on patients with drug abuse issue, and rights of Roma patients, in the second half of 2013 a brochure for patients’ rights with a focus on persons with intellectual disability was prepared. The brochure was designed with cooperation of the Association of citizens- Poraka (Message) and was printed in 3000 copies. The brochure was distributed to all 17 regional centres for support of persons with intellectual disability.

**Maintenance of a web page intended for practitioners and the general public.** The web page [www.health.rights.mk](http://www.health.rights.mk) serves as an important resource for information in the field of human rights, including rights of patients and is intended for the broader professional audience, as well as the general public, i.e. the patients.

After establishing of the web page and setting up of relevant content in 2012, in 2013 followed a process of daily maintenance and upgrading. During this period, the web page was updated with relevant publications that refer to various health issues, as well as international and domestic news. As an illustration, during 2013, 197 publications, 27 preventive and curative programs of the Ministry of Health, 219 domestic news and 692 international news were placed on the web page.

In the same year, 7255 unique visitors visited the page [www.healthrights.mk](http://www.healthrights.mk), and a total of 11.096 visits were made.



### **Distributing the Guidelines for practitioners and Brochures for patient rights.**

The brochures that were prepared within the initiative “Human rights in health care” were distributed to more universities, i.e. the law faculties in the following universities (University “Ss. Cyril and Methodius”, MIT University, SEE University, FON University, University American College and European University). The general brochure for patient rights in 1650 copies was distributed to the Association of doctors of social medicine. Another 50 general brochures were distributed to 30 Public Health Centres and their branch offices, and the Institute of Public Health of RM. Copies of the brochures were given away at the trainings and the working meeting organized by ESE.

### **International mechanism for protection of human rights, including the right to health-Universal Periodic Review.**

Within this activity, i.e. process, a number of activities have been initiated for preparation of a joint paper for conducting the health rights by ESE.

First, a training was conducted for the association of citizens that work on health care issues of marginalized communities, under the title “Preparation of a joint paper for health care within UPR”. The training took place on 13 and 14 March by Mariana Berbec Rostas, Open Society Foundation from Budapest. The training was realized with technical assistance and expert help secured by the Open Society Foundations New York and Macedonia. At the training, 10 representatives from the civic sector were present, three representatives of the Open Society Foundation Macedonia, five representatives of the ESE Association, as well as five top professionals and lawyers who work on health issues.

The objective of the training was familiarizing the representatives of the citizens’ sector, as well as the legal professionals with this international mechanism, but also with the process of preparation of a joint paper to the Human Rights Council of United Nations.

Additionally, through work in groups the participants were enabled to identify priority health care issues that the target groups face and that have to be integrated in the joint paper for health care.

After the ESE training, the process of preparation of the joint paper started. The following associations of citizens agreed on further participation in the process of preparation of this document: KHAM, Delcevo; Roma SOS, Prilep; Roma Resource Centre, National Roma Centre, LGBT at the Helsinki Committee, PORAKA, Open Gate- La Strada, HERA, HOPS, and the Coalition “Sexual and health rights of marginalized communities”. The consultation process through organizing three working meetings was organized and facilitated by ESE. During the working sessions, each of the included organization contributed with concrete suggestions for improvement of the individual organization’s texts, but also suggestions regarding formulation of certain messages for improvement of the conditions.

For the purposes of this process, the association prepared: guidelines for the organization for preparation of individual texts for the right to health of individual vulnerable groups, draft structure of the joint paper and preparation of list of requests for acquiring public information. After the writing of individual texts at an organization level, the association ESE was working on

revising and formulating content, summarizing and final draft of the individual texts into one joint final document, prepared according UN standards for preparation of a submission to the Human Rights Council.

As a part of the process of UPR of the Council for Human Rights in Geneva, on 29 November 2013, an ESE representative presented the key areas of concern and the recommendations for promotion of the health status of several vulnerable groups in R. Macedonia, i.e.: **Roma, people living with HIV/AIDS, LGBT persons, women, persons with intellectual disability and human trafficking victims**. The visit at the pre-session also included presentation of the conditions in R. Macedonia regarding the entire corpus of human rights, as well as activities for promotion of the conditions since 2009 (the first cycle of reporting of RM) until the second cycle of reporting, i.e. February 2014. Additionally, for advocacy purposes, we submitted the following documents: joint paper, list of key findings and recommendations and a copy of the speech prepared for the session, to the permanent missions of the UN member states.

These documents were sent in electronic format to the permanent missions of the countries that weren't present at the pre-session, in order to be used in formulating their recommendations to R. Macedonia at the official 18 Session.

After the pre-session, the working group for UPR prepared a Summary Session for the Council of Human Rights in December, as a compilation of all the documents that they had received by the state, international institutions and national citizens' associations. The report "Right to Health" encompassed all crucial findings that were presented in the joint paper of ESE and 10 citizens' associations.

**Preparation of video advocacy.** ESE and KHAM Delcevo, financed by the Foundations Open Society New York and Macedonia, produced a short video, titled: Barriers for access to the health care of Roma. The video illustrates the barriers that Roma face when they try to access health care, i.e. more precisely the refusal of the ambulance to provide services to Roma people. The person in the video is not the only one that was denied timely health care through the services of the ambulance, and thus ESE suggested inclusion of several more associations of citizens in a campaign that has the following purpose: **Securing timely emergency health care for the Roma**. The following organization expressed interest to become part in the advocacy actions, i.e.: Roma Resource Centre, CDRIM, LIL, HOPS, HERA, Coalition "Sexual and health rights of the marginalized communities, ROMA SOS and National Roma Centre.

The basic tool that was used in the process for advocacy to the health authorities, i.e. the Ministry of Health is signing of an "online" petition, by all interested parties. The petition was published on change.org. The video and the petition were published on the home page of ESE, as well as the thematic web page [www.healthrights.mk](http://www.healthrights.mk). Apart from this, the participating organizations contributed to spreading the video, sharing it on their web pages, social networks, electronic media and printed media. The ESE staff attended training about filming health rights violations before filming the video. The training took place June 12- 14 in Geneva.

#### **Capacity building activities in the field of human rights in health care.**

In 2013, two trainings took place: "Strategic advocacy in cases of human rights violations in the health care system" and training titled "Human Rights in Health Care". The training "Strategic advocacy of human rights violations in the system of health care cases" was carried out

September 4- 5 in hotel Arka, Skopje. The training was carried out with the organization INTERRIGHTS from England, whose primary mandate is court advocacy of strategic cases of human rights violation. The two-day training was conducted by a representative of the INTERRIGHTS organization, regarding questions related to the concept of strategic advocacy of cases, and by an expert with a significant experience in representing cases to the European Human Rights Court.

ESE's partner organizations were invited to attend the training, in order to promote the right to health and vulnerable groups of the population: HOPS- options for healthy life, Coalition "Sexual and health rights of marginalized communities", Open Gate- La Strada Macedonia, KHAM Delcevo, LGBT Center at the Helsinki Committee of Human Rights of Republic of Macedonia, Association for health education and research (HERA), Macedonian association of young legal professionals and Foundation Open Society Macedonia.

As part of the process of informing and the concept of human rights in health care, during the period 22 and 23 June, a two-day training was held in Skopje intended for a new group of participants, i.e. representatives of associations of patients. Representatives of the Ministry of Health, State Sanitary and Health Inspectorate, and the Committee of Skopje for protection of rights of patients and the association ESE were instructors at this training.

Representatives of the following nine organizations were present at the training: Macedonian scientific autism association, Association of patients with kidney diseases- Nefron, Association of patients with rare diseases "Life with Challenges", Association of patients with haemophilia "Hemolog", Federation of Associations of patients with diabetes, CDRIM, as well as representatives of the Public Health Care institution- General Hospital "8<sup>th</sup> September". The training's goal was to present the concept of human rights in health care, legal regulation regarding right to health and health care, patient's rights in the field of health insurance, the role of DSZI and protection of patients' rights at a local level.

In 2013, the following results were achieved:

- Updated content of the Guidelines for practitioners through analysis of domestic regulations in the area of health care and identified need to update it;
- Strengthened and extended cooperation with practitioners and representatives of citizen organizations in the field of protection of patients' rights through organization of two trainings;
- Reporting to international bodies of human rights within the United Nations Organization (Human Rights Council) through a development of a shadow report (Universal Periodic Report) for the degree of exercising human rights in Republic of Macedonia;
- Improved reporting, i.e. familiarization of the associations of patients with: basic human rights in health care through the Guidelines for human rights in health care; domestic legislation and methods of protection of the right to health in our country;
- Rights and obligations of patients to health care and health insurance; institutions that work in the field of provision of health care, health insurance and legal protection in our country, mechanisms for protection of the right to health, as well as the news in the field of protection of patients' rights;

- Increased awareness of the patients' rights of the general population and the population- members of marginalized groups, especially people with intellectual disability through preparation of a brochure together with association of citizens that have extended experience in this area;
- Preparation of video material for advocacy through presenting a real case of health right violation in Republic of Macedonia;
- Design and publishing of a newspaper article "Health and human rights" for the Harvard University.

## **PARALEGAL ASSISTANCE AND FACILITATION OF THE ACCESS TO PROTECTION OF THE RIGHT TO HEALTH CARE, HEALTH INSURANCE AND PROTECTION OF PATIENTS' RIGHTS**

During 2013, ESE continued its efforts to improve establishment of the concept of paralegal assistance in the area of health care for the Roma and securing support of the local Roma partner organizations. The paralegal assistance programs function within these organizations and they provide for support and overcoming the identified health problems and realization of the health issues of the local Roma population. The necessity for extending the efforts that the organization is undertaking in this field is more than justified, if we know that the identified problems that the Roma is facing regarding health care, health insurance and patients' rights protection still exist, and have significant influence to the access to services and quality of health care that this marginalized group uses.

Activities that were carried out during 2013, represent continuation of the accomplished results, and improvement of the work on the programmes for paralegal assistance in the partner organizations. ESE continued with activities that enhance institutional capacity, as well as human resources (coordinators and paralegal professionals) in the programmes for paralegal assistance. Activities at the level of partner Roma organizations and PR in the community were taking place simultaneously with the programmes for paralegal assistance.

Paralegal assistance and support is provided via the following partner organizations: Centre for democratic development and initiative- CDRIM, Roma Resource Centre from Suto Orizari and Humanitarian and welfare association of Roma, KHAM from Delcevo.

The following activities were carried out in order to strengthen local Roma partner organization capacities:

- **Trainings for the programmes for paralegal assistance.** During 2013, ESE continued organizing activities aimed at institutional strengthening of the capacities of the paralegal assistance projects. Coordinators' and paralegal professionals' education took place based on previously identified needs of the local Roma population through the work of the programs for paralegal assistance, thus in the period from 1- 3 March 2013, a training took place for the coordinators and paralegal professionals from three partner Roma organizations in the hotel Best Western, Skopje. The focus of the training was placed on the strengthening of their knowledge and skills in the area of labour market

and Roma rights in this area. The training was attended by 11 participants, 4 representatives from ESE and one trainer (a total of 16 persons).

- The second training included the following content: employment contracts, rights and responsibilities during employment, registering employees at the Employment Agency, prohibition of discrimination, termination of an employment agreement, paid and unpaid leave and inactive employment status, health care and safety at work, State labour inspectorate. On 15 April 2013, in the GEM Club in Skopje, the training focusing on non-discrimination took place. The training was attended by 9 (nine) participants and two ESE representatives, and one trainer (12 persons total). The third training included the following content: discrimination, discrimination grounds and forms of discrimination (through examples of discrimination on several grounds, racial, national and discrimination based on a disability); procedure for the Committee for protection of discrimination and court protection. It is significant to mention that the last part of the session was focused on the work of the Committee for protection of discrimination, i.e. the competence and proceeding upon submitted complaint for discrimination. At this session, Roma organizations presented cases of discrimination identified during the provision of paralegal assistance, and received practical advice regarding identification of discriminatory acts. During the period 18- 20 October in Skopje the initial training for the Roma partner organizations took place. The training was a reiteration of the initial training that was organized in the framework of the previous annual programme and it contained the following components: system of health care in R. Macedonia, protection of patient's rights, health insurance rights and the role of the State Health and Sanitary Inspectorate. The concept was envisioned and the presentations were prepared in a way that enabled the people who have already attended the training to refresh their knowledge, while the new paralegals had the opportunity to gain fundamental knowledge and skills for provision of paralegal assistance in their communities. Ten (10) participants attended the training, two representatives from ESE and three trainers (total of 14 persons). The last session of the training was dedicated to planning of activities at a local level by each of the programmes for paralegal assistance. Apart from the regular provision of paralegal services, other promotional and educational services were planned, including timeline for their completion.
- **Establishing a library of resources.** ESE continuously provides support to the programmes for paralegal assistance through regular informing of the changes and news in the health care system. During the previous period, ESE electronically disseminated information on latest changes and amendments in the legal regulations, guidelines and other types of documents that are required for the work of the programmes for paralegal assistance. Such regular reporting provides for self-training of paralegal professionals and improvement of their knowledge and skills for exercising of the right to health care, health insurance and protection of patients' rights. In 2013, ESE started and completed the preparatory phase for setting up of electronic library with necessary resources for the work of the programmes for paralegal assistance. The library shall be accessible in the existing web page of the organization, and coordinators and paralegal professional can use materials by registering in the library. The library contains several components, i.e.: relevant international documents and mechanisms for protection of human rights; national legal framework for protection of human rights;

laws in the area of health care, health insurance and protection of patients' rights; other laws and regulations in the area of health care; preventive and curative programmes of the Ministry of Health; mechanisms for protection of human rights in the area of health care; laws and other regulations in the area of social care; working documents; training materials; forms and instruction books and additional reference literature in the area of provision of paralegal assistance.

- **Upgrade of administrative procedures.** In accordance with the needs of the programmes for paralegal assistance, ESE started concrete activities aimed at improvement of the system for collection of data and case management. During the reporting period, several new forms were introduced in the programmes for paralegal assistance. It is important to mention that the visits to the programmes for paralegal assistance that were introduced this year enable continuous monitoring of the functioning of the administrative procedures in the programmes for paralegal assistance.
- **Monitoring, support and evaluation of the work of the paralegal professionals.** Apart from the regular activities that are undertaken in this area, such as the regular communication and periodic reporting by the coordinators and paralegal professionals, it is important to mention that direct visits were introduced, as an additional mechanism for monitoring of the work of the programmes and quality assurance of the programmes. The aim of the direct visits was to monitor the work of the programmes for paralegal assistance and to prepare concrete recommendations for improvement of certain aspects of it. During the reporting period, ESE conducted the first direct visits of the programmes for paralegal assistance at the end of 2013, prepared a report with recommendations for each of the programmes and submitted them to the partner organizations in order to improve the system for data collection and case management, as well as the programmes for paralegal assistance in general.

In the framework of activities aimed at providing paralegal assistance and support to the local communities, the following activities were completed:

- **Selection and hiring of a paralegal professional in the village of Crnik, municipality of Pehcevo.** In the partner organization KHAM, a paralegal professional was hired for provision of counselling and support in the v. Crnik, located in the municipality of Pehcevo. The necessity of establishing a programme for paralegal assistance in this village was more than justified, since it is a village with 40% Roma population, facing many forms of social exclusion of all aspects of the social life, including health care. In this situation, it is a mitigating circumstance that the KHAM organization is already actively participating in the resolution of the local problems and needs of this village and it has been recognized as such, by the local Roma community. Apart from the participation in the initial training in October, during the period after the beginning of work with the new paralegal, s/he spent a certain time working together with the paralegals of KHAM in order get ready for offering this type of counsel and support. The paralegal then continued working in the v. Crnik, in the offices provided by municipality of Pehcevo.

- **Providing paralegal assistance and support.** During 2013, the programmes for paralegal assistance provided support and help for 391 client. The information about each of the programmes for paralegal assistance have been presented individually in the following section: **Centre for democratic development and initiative (CDRIM) Suto Orizari.** Total of 87 clients contacted the centre in 2013, and the dominant number of cases involves exercising of the right to health care, health insurance and patients' rights. Basic counselling was provided for all cases, which includes legal mechanisms for protection of the rights in the area of health care, while for some of the cases, referral to certain health centres was provided, i.e. a written form was prepared. Apart from the health cases, clients addressed the centre for cases in social care, such as: right to social welfare, right to care from others, permanent allowance, right to complaint, etc. A smaller number of clients requested assistance for securing personal documentation for exercising rights in education and employment.
  
- **Roma Resurce Center (RRC) Suto Orizari.** During 2013, 114 clients requested assistance from the programme for paralegal assistance in RRC. In most cases, they requested assistance for exercising their rights in the area of health care, health insurance and patients' rights. Most clients requested assistance for provision of an electronic health card and health insurance; referrals and escort of clients to the competent health care institutions; scheduling visits and treatment at a tertiary level. In several cases, the paralegals prepared legal documents on behalf of the clients for requesting one-time financial assistance, for treatment or an operation. In about 20 cases, help was provided for exercising concrete rights in the area of social care, such as: right to social welfare; permanent allowance, right to complaint due to terminated right, etc. **KHAM- Delcevo.** During reporting period the centre was visited by 190 clients. The majority of clients requested assistance for protection of their rights in health care, health insurance and patients' rights. Part of the services that were provided by the paralegal professionals were: scheduling doctor's appointments (specialist, gynaecologist, paediatrician, etc.); referrals and escort of clients to health care institutions; drafting requests for compensation of medicines and operation; filing a complaint against unprofessional doctor's treatment, etc. A number of cases were regarding the right to care from others. Apart from the right to health, local Roma population to a great extent faces difficulties in exercising the right to social care and this is evident through the increased number of cases such as: right to social welfare; permanent allowance, requests for one-time financial assistance, complaints for termination of welfare, etc. Apart from providing assistance and support in individual cases, the paralegal assistance programme was active also in addressing certain collective needs of the community, and such case is the joint project with the elementary school "Vanco Prke" for provision of free food for 12 students coming from socially vulnerable families, most of them Roma.
  
- **Organizing promotional activities (door to door).** Paralegals organized activities continuously. They visited over 700 Roma families and informed them of the types of services they provide through the programmes for legal assistance in their communities.

- **Organization of educational workshops.** During 2013, eight educational workshops were organized, i.e. four workshops in municipality of Suto Orizari (by CDRIM and RRC) and four in Delcevo, i.e. in the village of Crnik (by KHAM). In the first half of 2013, KHAM organized two educational workshops about patients' rights, reimbursement of funds and spa treatments. One of the workshops was organized in Delcevo, while the other one in the village Crnik, in the municipality of Pehcevo.
  
- Representative from HIFM addressed the audience and informed them how they can receive the rights in health care they are entitled to. The two workshops were attended by 60 participants. After the workshops their findings and receipts were discussed, and they were offered assistance with respect to their health rights. In the second half of 2013 in Delcevo and Crnik two educational workshops were organized, entitled "Help and care for another person". Each of the trainings was attended by 25- 30 participants. Representatives from the Centre for social work (CSW) from Delcevo and Berovo, responsible for issues regarding the right to other's care addressed the participants and informed them how they can benefit from their right. In June 2013 in the premises of RRC an educational workshop entitled "Health cards- new change in health care and obligations for citizens" was organized for the people of Suto Orizari. The training was attended by 35 students, representatives of RRC and one instructor. In December 2013, an educational training entitled "Patients' Rights" took place, focusing on the right of the patient to agreement, i.e. signing consent statements by patients. This workshop was delivered by paralegals and coordinator of RRC, and it improved visibility of the organization in the community. In May 2013, CDRIM organized educational workshop entitled "Right to permanent allowance- care of another person". The event was attended by 28 participants, representatives of CDRIM and one instructor. During the workshop, the participants stressed the problems that they face in the process of exercising the right to assistance and care of other person, and they were informed by the instructor in more detail about the way they can exercise this right, criteria that have to be met and the documents that is required. In the month of June 2013 training was held, entitled "Exercising the right of social care". The training was attended by 27 participants, representatives of CDRIM and an instructor- representative of CSR. The workshop was organized in order to inform the local Roma population of the way they can exercise their rights in the area of social welfare, in a situation when most of the users of social welfare in the municipality are faced with termination of this service.
  
- **Organizing meetings with relevant actors at a local level.** During 2013, several meetings with relevant actors were organized on a local level, by local Roma partner organizations. The goal of these meetings is to determine the directions for cooperation and to coordinate the activities of all institutions that participate in provision of health care for the Roma at a local level.

### **NATIONAL CONFERENCE "Roma Health - Access, Challenges and Improvement Opportunities"**

ESE and Roma partner organizations CDRIM, RRC, LIL and KHAM organized the national conference "Roma Health - Access, Challenges and Improvement Opportunities", on 8



November, 2013. The goal was to present the basic concepts for improvement of the access to health care services and exercising the rights in the area of health care of Roma, that in the past years were applied by the ESE and partner organizations with the support of the Foundation Open Society Macedonia. The conference was opened by Jasminka Friscik, Executive Director of the Association ESE and Suzana Velkovska, Coordinator of the Programme for Public Health at FOSM.

Two plenary sessions were held at the national conference:

***Plenary Session 1 – Improved access and increased opportunities for accomplishment of the health rights of Roma through securing of paralegal/legal assistance and support.***

The concept of securing paralegal assistance in the area of health care was presented, as well as the results of the work of the programmes for paralegal assistance in the municipalities Suto Orizari and Delcevo. The concepts of paralegal and legal assistance were differentiated, and opportunities were identified for their harmonization and mutual strengthening. On this session, ESE representatives and representatives of partner organizations that are included in the project, CDRIM, RRC and KHAM addressed the participants, as well as other representatives who implement similar initiatives in the area of promotion of Roma health, such as Roma SOS and the HERA Association. The following speakers addressed the audience: Stojan Misev, moderator at ESE; Zoran Bikovski, coordinator at KHAM; Fatima Osmanovska, coordinator at RRC; Serhan Ismail, coordinator at CDRIM; Romina Kajtazova, paralegal at KHAM; Aleksandar Petrusoski, paralegal at RRC; Darko Kocevski, paralegal at CDRIM; Tanje Trenkovska, lawyer at Roma SOS and Igor Krstevski, lawyer at HERA. Participants at the conference were informed about the process of establishment of programmes for paralegal assistance and efforts that were devoted by ESE, including support provided for the local partner organizations before and after establishment of programmes for paralegal assistance in their communities. Institutional strengthening and continuous activities for capacity building that are provided by ESE are necessary for proper set up and functioning of the programmes for paralegal assistance.

At this session, results were also presented from the work of the programmes for paralegal assistance, including number of users and type of provided services by the paralegal professionals.

Conference participants had the opportunity to learn about the dominant problems of Roma in the area of health care, as well as the challenges that the paralegals face when they address these problems. It is significant to note that one client expressed her gratitude of the provided assistance and support. Apart ESE partners, at the conference other representatives of other organizations that provide paralegal assistance were also speaking (HERA and ROMA SOS).

***Plenary Session 2 – Approaches to monitoring of budgets and monitoring of community aimed at improvement of the health care of Roma at a local level.*** Borjan Pavlovski from ESE was moderator at this planetary session, and guest presenters were: Kemal Ismail from CDRIM, Elena Kostovska from LIL and Romina Kajtazova from KHAM. Within this session the following was presented: report on the actual situation of Roma children and immunization coverage and preventive health services in their municipalities; main problems that Roma face when accessing preventive health services; how and why the community is included in the process of

defining a problem, monitoring of health services and advocacy for change; major changes that have been achieved in the area of Roma coverage with preventive health services.

From the presentations and discussion in this session we can conclude that through the application of the two approaches- monitoring of budgets and monitoring of the community, partner organizations can clearly identify major drawbacks, prepare improvement for recommendations, as well as successful advocacy at a local and national level. This is even more important, since the entire work has been based on proof and the inclusion of the local Roma community is emphasized.

The following results were achieved in 2013:

- A new person was identified for providing of a paralegal assistance and support for the village Crnik, municipality of Pehcevo;
- Broadened knowledge and skills of the larger population of paralegal professionals regarding the concept of paralegal assistance; the setup of the health care system; rights in the area of health care; health insurance and patients' rights through carrying out of initial training;
- Increased knowledge and skills of extended group of paralegals in the area of non-discrimination and labour relations;
- Established direct visits as a new mechanism for monitoring of the quality of paralegal assistance programs;
- Organized first direct visits in the programmes for paralegal assistance within the partner Roma organizations;
- Organized a range of educational workshops with the local population;
- Upgrade administrative procedures for collection of data and case management.

## **FISCAL TRANSPARENCY AND ACCOUNTABILITY OF PUBLIC INSTITUTIONS**

Throughout 2013, ESE continuously carried out activities for promotion of the transparency in the operations of the government institutions, especially the institutions of the public health sector.

**Procedure for accessing public information.** Through the procedure for access to public information, the target institutions were requested copies of documents that they are required to provide during the process of planning and realization of the programmes for preventive health care and budgets, otherwise not publicly available. For this purpose, we requested copies of the mandatory financial/treasury and programme documents that the implementers of the activities are obliged to prepare. These documents were requested from each implementer .

During the year, we prepared total of 433 requests in 37 state institutions for request of information. During the procedure, we submitted 260 complaints and 57 objections to the Committee for protection of the right to free access to public data, because of no-response of the institutions and unsatisfactory quality of the received responses. The Committee responded to

237 complaints submitted by ESE, and adopted 36 resolutions with ESE's explanations, and tasked the information holders to submit requested information to ESE. Regarding the other claims, the Committee decided on termination of the procedure, explaining that the holder of the information provided the requested information. Since 18 of the adopted resolutions of the Committee were not processed further, and since we were entitled to protective measures for securing needed information, ESE submitted 18 complaints to the State Management Inspectorate of R. Macedonia. None of the complaints received a positive response.

During the process for requesting information that is public, in the process for selection of a publicly available documents related to our case of analysis, as well as during the process of implementation of activities, during 2013 ESE cooperated with: legal program of FOSM and the permanent external collaborators of ESE.

**Meetings with authorized persons from the target institutions.** During the procedure for requesting public information, three meetings with authorized personnel were held: A meeting with representatives of PHI Health Center- Skopje and the Sector for preventive health care at the Ministry of Health (Nermina Fakovic- Coordinator for the programme for active health care of mothers and children and Sanja Szardovska- Coordinator for implementation of the Programme for early detection of malignant diseases, component for screening of a cervix carcinoma); two-day working meeting with citizens' organizations, representatives of the Committee for protection of the right to free access of public information of RM (KOMSPI) and representatives of the Committee for protection of the right to free access to public data of Slovenia, organized by KOMSPI.

**Monitoring of internet pages of public institutions.**

During this period, ESE monitored internet pages of seven public institutions: Ministry of Finance, Ministry of Health, Health Insurance Fund, Health Centre- Skopje, Municipality of Kocani, Municipality of Tetovo and Public Health Institute. During this process, we identified the availability of basic documents that the institutions have to prepare during the budget process. Apart from that, we monitored other indicators, i.e.: whether the institutions have their own web page; have they published their strategy/ strategic priorities of the institution, and the last year that such a document has been published for; do they publish their annual working programme, and the last year such a document has been published for; do they publish the budget and the last year a budget has been published for; do they publish monthly, biannual, and annual budget reports and the last year they have been published for; do they publish contact information of the authorized staff for mediation of the process for requesting public information and the process for exercising the right to access public information.

**Activities for awareness rising of public institutions for the need and significance of transparent and accountable operations, followed by advocacy.**

Throughout 2013, a range of activities have been completed, including: participation in the research implemented by FOSM that was supposed to evaluate the process of use of the Law on free access to public information by the citizen organizations and citizens; submitted draft for changes and amendments of the Law on free access to public information in the Ministry of Justice (working group for change and amendments of the Law on free access to public information), promotion of results of the research for evaluation of the citizens inclusion in the

decision making process and the budget process in the municipalities of Kocani and Tetovo, on the occasion of the international day "Right to Know".

**Maintenance of the internet page of ESE, the section for promotion of transparency and accountability of public institutions.** ESE dedicated a special section on the internet page for the importance and the significance of fiscal transparency and accountability in detail.

More precisely, we published all relevant regulations and information for access to public information, the participation in the work of the public institutions, monitoring of the work of public institutions, as well as the responsibility of the Government and the governmental institutions for publishing of information and transparent and accountable operations.

We also presented all significant international initiatives for promotion of transparency and accountability of the operations of the government and all indexes and data that is used to evaluate the level of transparency and accountability of operations of the government in R. Macedonia. We also published information acquired through the procedures for access to public information that ESE has completed in the previous years.

**Memberships in international transparency and accountability networks.**

In 2013, ESE signed the Dar- Es- Salaam Declaration and became a part of the global movement for budget transparency, accountability and participation (BTAP). We became a part of the network of organizations that work in the field of monitoring and analysis of budgets, budget transparency and participation, as led by the IBP (International Budget Partnership) and the network of citizens' organizations that monitor the enforcement of the process of implementation of the initiative of the Open Government Partnership. As a result of the membership in these networks, a range of documents have been drafted, and a number of joint initiatives established for promotion of fiscal transparency of public institutions.

**Carried out analysis of total and public expenses in health care in RM.**

In 2013, we prepared an analysis of the total expenses for health care in R. Macedonia and analysis of the public expenses. This analysis demonstrated worrying data of the way public money is managed, as well as their allocation and use. We faced problems and obstacles for providing public data for this analysis as well. The results of these analyses are summarized and shall be used in the further process of advocacy.

**Established closer cooperation with the president of the Parliamentary Committee for financing and budget and we attended the 77<sup>th</sup> session of the Committee.**

In October 2013, upon ESE's request, a representative of ESE attended the 77<sup>th</sup> session of the Parliamentary Committee for financing and budget. On this session, the members of this Committee discussed the governmental proposal for changes and amendments of the budget of RM for 2013. Through the presence at the session, ESE aimed to learn more about the work of the Committee, as well as their members. We managed to establish a closer cooperation with the president of the Committee for financing and budget, Marjancho Nikolovski and the representatives. This cooperation shall serve further strengthening of cooperation and facilitation of the communication with the Committee and its members.

These activities in 2013 led to the following results:

- Drafted 433 requests for access to public information to 37 public institutions;
- Filed 260 complaints and 57 objections to the Committee for protection of the right to free access to public information and 18 complaints to the State Management Inspectorate of R. Macedonia;
- Adopted 36 resolutions for adoption of the filed complaints and tasking of information holders for securing a requested information, by the Committee;
- Accomplished direct meetings with authorized personnel in: PHI Health Centre- Skopje, Committee for protection of the right to free access to public information of RM (KOMSPI) and representatives of the Committee for the protection of the right to free access of public information from Slovenia and representatives of the Sector for preventive health care from the Ministry of Health;
- Developed methodology for monitoring of internet pages of public institutions, in order to identify degree of transparency and accountability of the pages and monitoring of internet pages of seven public institutions using the developed methodology;
- Published documents from public institutions acquired upon request for public information on the web page of ESE;
- Membership of ESE in the Global movement for budget transparency, accountability and participation (BTAP) and the Group of citizens associations for Open Government Partnership;
- Initiative for preparation and proposal of activities in the Action plan for Open Government Partnership 2014- 2016, including 8 other citizens organizations;
- Prepared analysis of total and public expenses in health care in R. Macedonia; and
- Established cooperation with the Committee for financing and budget at the Parliament of RM and attendance at one committee session regarding proposed amendments in the budget of RM for 2013.

## **EQUAL OPPORTUNITIES FOR WOMEN AND MEN**

## **MONITORING AND PROTECTION OF WOMEN'S HUMAN RIGHTS- TRAINING FOR CITIZENS' ORGANIZATIONS**

ESE and the International Women's Rights Action Watch- IWRAP Asia Pacific organized a three day workshop, entitled "Consultations about the implementation of the Convention CEDAW and concluding recommendations aiming to promote gender equality in Republic of Macedonia". The workshop was held in Skopje, from 15- 17 March. The following organizations took part in the workshop: Open Gate- La Strada, HERA, Akcija Združenska, Female forum Tetovo, FOSM, HOPS, Coalition "Sexual and health rights of marginalized communities", Organization of women of the city of Skopje, Union of independent trade unions and Roma Centre- Skopje.

This workshop is part of the activities that ESE undertakes in the field of monitoring of female human rights and independent reporting about the situation in front of the international bodies, especially the Committee of the United Nations responsible for monitoring and implementation of the Convention CEDAW. At the 54<sup>th</sup> Session of the Committee, held in 2013, Republic of Macedonia reported on the implementation of the provisions of the Convention (fourth and fifth report), while ESE and Akcija Združenska reported on the conditions on the basis of the prepared shadow reports.

The shadow report was prepared with the help and cooperation of twelve citizen's organizations. The workshop's objective was to improve the knowledge and skills of the representatives of relevant citizens' associations regarding the usefulness of the Convention, as well as to provide a broad consultative process in order to further monitor the implementation of the adopted recommendations of the Committee about our country. Part of the training was organized in group work, and the teams were working on identifying the situation regarding: violence against women; human trafficking; marginalized groups and communities (LGBT population, drug users, people living with HIV, and violence against these groups of people); traditional values and position of Roma women. The concluding part of the training was focused on identifying and developing plan for advocacy and proposal of concrete actions that aim to monitor the implementation of the Final recommendations regarding the above listed gender issues. The implementation of the Final recommendations regarding violence against women, that our country is to report on in 2015, shall be specifically monitored.

## **PROVIDING LEGAL, PSYCHOLOGICAL AND HEALTH INFORMATION AND ASSISTANCE TO VULNERABLE CATEGORIES OF WOMEN**

**Legal assistance centre for help to women, victims of family violence.** During 2013, the centre of legal assistance of ESE continued to provide legal assistance, counselling and referrals of clients to competent institutions for realization of their rights. Additionally, the ESE Association provided free advocacy for certain number of victims of family violence in the national courts. During 2013, total of 221 clients contacted the Centre for legal assistance of ESE for the first time. Legal assistance during this year was carried out through provision of legal assistance and support of women victims of family violence and marginalized groups (women living in poor socio-economic conditions, Roma women) through giving legal advice, preparation of written complaints (complaints, petitions, pleadings, etc. to competent institutions) as well as referrals of clients to competent institutions for exercising their rights. Additionally, legal advice and referrals were carried out by means of telephone calls for clients

who were not able to visit our offices. This year, total of 570 individual meetings for legal assistance were held in the Centre.

Of the total number of clients who contacted the Centre for legal assistance, 146 clients were interested in initiating divorce, and the process of a divorce itself. This number is significant and it is due to the fact that the victims of family violence see salvation from the situation that they are into, by starting a procedure for divorce. Regarding other issues, 94 of the clients were interested in child custody, 99 of the clients were interested in the payment or non-payment of alimony, 29 of clients were interested in property issues, 11 clients were interested in criminal cases and 2 female clients were interested in emergency protection from family violence, and we prepared for them a Proposal for imposing a temporary measures for protection of family violence. Regarding free advocacy of women victims in lawsuits (citizens and criminal) during 2013, total of six clients were represented in first instance courts. Two of the clients were represented in a procedure for imposing a temporary measure for protection of family violence, one in a procedure for changing a court decision for entrusting a child, one in a divorce procedure and child custody, one in a criminal charge for severe corporal injury, initiated by the Ministry of Interior ex officio investigation on a reported case of family violence.

**Counselling centre for victims of family violence.** In 2013, the assistance in the psychological centre was provided by a therapist once a week. During 2013, total of 59 patients contacted the centre, 41 of which for the first time. A total of 111 individual meetings were held. The centre is primarily offering assistance to women victims of family violence, but sometimes men or couples visit the centre, as well as children victims of family violence. During 2013, of the total number of clients that visited the centre for the first time, 39 were women and 2 were men. Thirty eight of the clients contacted the centre because of family violence. Psychological suffering has been registered at 35 of the clients, 26 experienced bodily violence, 10 economic and 14 sexual violence. The sexual violence, as a type of violence that the victims of family violence face has been on the rise in 2013. The perpetrator of family violence in most cases is the spouse, in total of 32 cases, in one case a former spouse, in 4 cases relatives, i.e. daughter, son, father and mother in law, and in one case an extramarital partner. The psychologist had 81 counselling sessions, 27 therapeutic interventions, and 26 psychological interventions in 2013. Part of the clients were advised to visit competent institutions, one client was scheduled at the Centre for mental health of children and youth and one client was referred at a psychiatrist's office. Four of the clients were referred at the lawyer of the Legal assistance centre of ESE, and one client was advised to take her child at the Centre for mental health of children and youth for a paediatrician's examination.

After the counselling, for 3 of the clients there was no change of the state, for 16 of the clients an improvement of the psychological condition was registered, five improved communication with their families, three are still in therapy and for 17 of the clients we don't have feedback, since they haven't scheduled a session.

**Health information centre.**

The health information centre during the entire year provides health advises to women via telephone and direct meetings; provides information for the place and type of health services that women need; provides direct health services such as blood tests: blood sugar, cholesterol, triglycerides, and blood pressure monitoring. In 2013, total of 48 clients visited the health information centre for counselling or use of direct services. Thirty two of the clients visited the



centre for services related to osteoporosis, while 16 visited the centre for blood tests and blood pressure monitoring.

**Organization of a New Year's party.** During the month of October 2013, 26 requests for donations were delivered to organizations from R. Macedonia. The organizations have been requested to donate part of their line of products, intended for preparation of holiday gift packages for the victims of family violence. The requests were delivered via e-mail to the official e-mail addresses of the potential donors and via fax. Six of the companies we contacted responded and took part in the project. Guests at the party were 38 children with their parents, clients of the Centre for legal assistance and the Psychological counselling centre of ESE, as well as representatives from the donor organizations and the ESE personnel. Forty- two gift packages were delivered. The Skopje ZOO, Rotary Club Skopje, Makprogres Vinica, Vincini, Office Plus and Ramstore were supporters of the party. The New Year's party is part of the Working Programme of ESE for 2013.

The following results were achieved in 2013:

- 221 new clients addressed the Centre for legal assistance for victims of family violence;
- 570 individual sessions for providing of legal assistance and support completed;
- 146 pleadings prepared about divorce, custody (94), payment/non-payment of alimony (99), property cases (29) and criminal cases (11);
- 81 advisory sessions, 27 therapeutic interventions, 26 psychological interventions within the Psychological counselling centre;
- Registered improvement of the psychological condition of 16 women clients, 5 improved quality of communication with their families, three are still in therapy;
- 48 people used the services of the Health Information Centre (getting health information and receiving direct health services);
- Organized New Year's party and delivered holiday gift packages for 42 children.

## **PROVIDING COURT PROTECTION DURING IMPOSED TEMPORARY PROTECTIVE MEASURES AGAINST FAMILY VIOLENCE**

Although they have been planned to be a cornerstone of the citizen's legal system for protection, the temporary measures for protection of victims of family violence have been insufficiently implemented by the institution that have a legal mandate to initiate, impose, enforce and monitor them. Temporary protective measures are to enable immediate and fast protection of the victims. Some of them have prohibitory character (they prohibit certain behavior of the perpetrator), and part have imperative character (they impose certain behavior of the perpetrator). These measures have not been adequately used for protection of victims in RM. On the one hand, victims have been insufficiently informed about protection that is supplied with these measures, and on the other, identified are concrete oversights on the part of relevant institutions.

Data from previously performed researches for institutional action<sup>1</sup> in cases of family violence point to lack of sensitivity and understanding by judges regarding the issue of family violence (nature and types), which results in partial imposing of proposed temporary protective measures. Judges often impose less than the proposed temporary measures, although there is a real need for that. The urgency of the procedure is not observed, i.e. in many cases these measures are imposed outside of the planned period. Therefore, instead on the first hearing, they are imposed on the tenth hearing. This prevents the protection of the victim of family violence, i.e. the victim is additionally exposed to even greater risk of violence.

For this reason, in 2013, ESE started with activities that shall enable significant improvement of the citizen legal system in the country, i.e. improvement of the system to provide faster, adequate and coordinated protection of victims of family violence. Activities encompass the women- victims of family violence, as well as judges involved in cases for imposing temporary measures against family violence in four trial courts in RM.

Women- victims of family violence were included in the implementation of the PLANNED activities in several ways, i.e. through: membership in the working group that drafts the form for monitoring of court cases; analysis of the findings and recommendations upon completed monitoring, and implementation of the survey that precedes the drafting of the Guide for procedure for imposing temporary measures for protection prepared for the women- victims of family violence.

Judges who impose temporary measures for protection of family violence, are also stakeholders in this project. They have been included in: monitoring court cases where they judge; participation on the individual meetings for review and discussing the findings and recommendations of the monitoring; and participation on the forum where they discuss all findings and recommendations (judges and representatives of participating courts).

During 2013, the following activities have been completed:

- **Establishment of cooperation with trial courts.** As planned, in September 2013, ESE drafted and sent a letter (request) for establishment of cooperation with four trial courts: Skopje, Bitola, Tetovo and Stip. The letter contained also a request for delivery of information about current procedures for imposing of TPM. During the month of October, the trial courts responded that they do not have in their records court cases for imposing temporary protective measures against family violence. Therefore, we decided to change the methodology of collecting the necessary information- review of completed court procedures. For this purpose, a request for cooperation and information (for on-going and completed court procedures) was delivered to all 27 trial courts in the country, and consequently, after the received response also delivered a request to selected courts to grant us access to completed court procedures of this type. After we received a response by the trial courts, we established cooperation with courts that delivered information about on-going or closed lawsuits, and a cooperation for **monitoring** of current court proceedings in several courts has been established: the courts in Strumica, Tetovo, Kumanovo, Bitola, Radovis, Stip and Debar.

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<sup>1</sup> Life in a Shadow, Research of the dark figure and institutional response in family violence, 2007, Association ESE

- **Drafting a form for monitoring (survey).** A team was formed for drafting the form for monitoring (questionnaire). It is significant to mention that women who are victims of family violence, and who have had experience with court trials, directly participated and were consulted regarding the questionnaire. The following profiles also participated in the team: criminal judge, citizen's judge, lawyers with experience in initiating such procedures (two lawyers), representatives from ESE and representatives from the Coalition "All for fair trials". Once the team was formed, ESE organized two working meetings, as well as additional electronic consultations, after which the questionnaire was completed. The survey remains a basis for collection of data from courts with regards to the lawsuit for imposing temporary protective measures (TPM) of the victims of family violence.
  
- **Identifying supervisors and organizing training for monitoring of court proceedings.** Considering the previous experience in the field of monitoring of court cases and credibility in this field, ESE engaged the Coalition "All for fair trials" in order to use their human resources for implementing of the process for acquiring data for court cases for imposing TPM. Cooperation with the Coalition was established in the process of planning of activities. Ten supervisors were identified by ESE and the Coalition. The supervisors are lawyers who have long term experience and capacity for on-going monitoring of court proceedings, and in this way they gained more knowledge and skills regarding family violence. The training was organized during the period 17- 18 December 2013 in the premises of GEM Club in Skopje. The training was delivered by representatives of ESE (the coordinator of the project), Stojan Mihov, judge in the Trial Court Stip, and Goce Sitnikoski, coordinator of Coalition "All for fair trial". The participants were informed in detail about: the nature, forms, advocacy and consequences of family violence; legal regulation in criminal and citizen legal system for protection with focus on the proceedings for imposing TPM; the contents of the form, supervising and review of court proceedings for imposing temporary measures for protection of family violence.
  
- **Monitoring of procedures for imposing temporary protective measures against family violence and collecting data.**
- In 2013 total of 13 court cases were monitored for temporary protective measures against family violence in the trial courts in: Strumica, Tetovo and Kumanovo. It is significant to mention that if during the upcoming period we receive information of initiated procedures of this type by other trial court, they will be subject to monitoring. The review in completed court procedures in the courts in Radovis, Stip, Bitola and Debar is planned to be realized in the month of January 2014.

The following results were achieved in 2013:

- Established cooperation in three trial courts for monitoring of ongoing cases (Strumica, Kumanovo and Tetovo) as well as cooperation with four trial courts for review of completed court lawsuits (Bitola, Stip, Debar, Radovis).
- Drafted research instrument (questionnaire);
- Identified 10 supervisors and they are trained for monitoring and review in court proceedings for temporary protective measures against family violence;

- Secured initial data about the method of court proceedings through supervision of on-going court lawsuits.

**FINANCIAL REPORT**  
**FOR THE PERIOD**  
**JANUARY 2013 – DECEMBER 2013**

## Revenue for 2013

<b>Revenue per item</b>	<b>Amount in MKD</b>
1. Transferred funds from the previous year	4.085.308
2. Revenue from memberships, gifts, donations and other sources	13.488.467
3. Revenue from interest and positive currency differences	31.713
4. Other revenue	432.438
<b>Total revenue</b>	<b>18.037.926</b>
Transferred for following program year (2014)	5.917.824

<b>Revenue from various grounds and donors</b>	<b>Amount in MKD</b>
<b>Revenue from grants and cooperation agreements</b>	
CIRa (CIVICA Mobilitas)	137.072
FOSM (Foundation Open Society Macedonia)	12.327.170
IWRAW -AP	354.156
IPPF	45.089
USAID civil society Project	577.870
ZG HERA	24.000
<b>Revenue from memberships</b>	13.500
<b>Revenue from donations of legal entities and individuals</b>	9.610
<b>Total</b>	<b>13.488.467</b>

### Expenses for 2013

<b>Grounds</b>	<b>Amount in MKD</b>
Programme costs and operational costs	7.453.130
Salaries	4.627.813
Capital expense	39.159
<b>Total</b>	<b>12.120.102</b>