

## REPUBLIC OF MACEDONIA

Shadow report for consideration by the Committee on Economic, Social and Cultural Rights at its 58<sup>th</sup> Session  
(58<sup>th</sup> session, 6-24 June, 2016)

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### Shadow report from Association for Emancipation, Solidarity and Equality of Women - ESE

With:

#### As regarding the Article 12 (Right to health)

Citizen Association KHAM,  
Health Education and Research Association - H.E.R.A.  
HOPS - Healthy Options Project Skopje  
Republic centre for support of persons with intellectual disability – Poraka  
Roma Resource Centre  
Center for Democratic Development and Initiative –CDRIM  
Roma Organization for Multicultural Affirmation - ROMA SOS Prilep  
Open Gate – La Strada, and  
The association of citizens for rare disease “Life with Challenges”

#### As regarding the Article 3 of the ICESCR (Right to gender equality)

Open Gate – La Strada and  
Coalition “Sexual and Health Rights of Marginalized Communities”

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## 1. INTRODUCTION

The Association for emancipation, solidarity and equality of women– ESE<sup>1</sup>, has been working for 25 years on promotion of social and economic justice in the areas of health care rights (women’s health, health of Roma people and patients’ rights), violence against women and equal opportunities for men and women through provision of direct aid, representation in improvement of laws and policies as well as documenting and reporting of cases of violation of human rights.

In cooperation with 9 other organizations of citizens with support of Open Society Foundation, New York and Macedonia, we put together this Shadow report to highlight the problems associated with non-fulfillment of the **Right to health** (article 12 of the ICESCR and General comment no.14) by several vulnerable groups: Roma people, people living with HIV/AIDS, drug users, women, people with rare diseases, people with intellectual disability and victims of trafficking in human beings. At the same time, the realization of the right to health of women and Roma has been analyzed from the perspective of the application of article 2.1 of the Treaty- Maximum use of available resources.

Also, the Shadow report includes findings from the Association ESE and two partner organizations carried out within the Women’s Legal protection project supported by the U.S. Agency for international development - USAID, for the implementation of the **Right to gender equality** (article 3 from ICESCR), including legal protection of different categories of women victims of violence and discrimination: domestic violence, trafficking in human beings, sexual work and psychological and sexual violence at the work place.

The Shadow report aims at contributing to the consideration and issuing Recommendations to the Government of Republic of Macedonia for the fulfillment the right to health and right to gender equality as regulated in the Covenant.

## 2. THE RIGHT TO HEALTH (Article 12 and General Comment no.14)

### 2.1 MAXIMUM USE OF AVAILABLE RESOURCES (Article 2.1. in correlation with article 12)

**The public budget health<sup>2</sup> of the Republic of Macedonia is not progressive.** The analysis of the Health Budget of the Republic of Macedonia shows that on average 16% of the total national budget was spent on health over the past ten years. The allocation of funds to different sectors does not apply the budgeting principle based on priorities; instead, it is based on the application of a pre-developed mathematical formula for allocation. Thence, such a budget fails to include funds and activities that would realistically meet the needs of citizens when it comes to health services and protection, leaving the health of citizens instead dependent on the overall budget policy of the Government of the Republic of Macedonia.<sup>3</sup>In the period 2012 to 2015, funds from the Central Budget of RM increased on average by 3%. The Budget of the Ministry of health accounts on average for 3% of the central budget and increases annually by 1% on average over this period. The increase in the budget of the Ministry of Health is due primarily to the increased funds allocated for salaries of public administration in the health care sector, procurement of equipment, reconstruction and construction of facilities etc. The Ministry of Health in the period 2012 to 2014 on average executes 90% of the approved budget. The unspent portion of the budget is largely accounted for by the preventive health care, i.e.20%,

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<sup>1</sup>Over the past five years, only in the area of health, the Association started applying several concepts which are considered to be new and innovative even at a global level, such as: budget monitoring and analysis; community monitoring; paralegal aid and support of Roma community etc. ESE applies new concepts and methodologies in order to improve the realization of human rights, in particular healthcare rights and in order to enhance the transparency and accountability of national and local institutions in the area of health and health care.

<sup>2</sup> The health budget of the Republic of Macedonia is a sum of the expenses of the Ministry of Health and the Health Insurance Fund of the Republic of Macedonia - FZOM (the FZOM budget also includes the expenses of the Public Health Institutions in the country).

<sup>3</sup> <http://esem.org.mk/pdf/Publikacii/2015/Alarm%2032.pdf>

compared to the unspent funds in curative care which on average stand at 2% annually. This practice of non-progressive allocation of funds for preventive health care programmes by the state is also exercised in case of the funds allocated for the implementation of the National Action Plan for Health of Roma People<sup>4</sup>.

**The public health budget of the Republic of Macedonia is not developmental.** The structure of the public health budget clearly indicates that most of the funds are spent on procurement of goods and services year in and year out. Over the past ten years, the funds earmarked for this purpose have been reduced by 11 percentage points (89% of the 2006 health budget were set aside for goods and services, while the same portion in 2016 went down to merely 78%). Over the same period, the health institutions rendered services for which they never received funds, which led to continuous negative financial results of their operation and continuous increase of their debt; this, in turn, resulted in a decrease in the quality of the health services. At the same time, at the cost of the amounts spent on goods and services, the subsidies and transfers expenses (transfers to public enterprises, private companies, and civil society organizations) kept rising to reach 590% more; the same trend was also noted in the case of capital expenses (construction facilities, equipment, vehicles, etc.) - the increase of this item amounted to 352% more than costs for goods and services.<sup>5</sup>

**The public health budget of the Republic of Macedonia fails to meet the principles of non-discrimination and equitable access for all in the provision of health services to different groups of citizens.** The 2016 health budget aimed at promoting the health of the Roma via support for and implementation of the Roma decade and strategy includes 29% less funds than in 2014.<sup>6</sup>

Guided by the recommendation given by the Special Rapporteur on the right to health<sup>7</sup> concerning the provision of balance between the curative and preventive health care, we can conclude that the Ministry of Health attached priority to curative health care which on average accounts for 46%, while it sets aside 7% of its budget for preventive health care. This prioritizing is evident in the continuous growth of the budget earmarked for curative health care (30% annually on average), while the budget for preventive health care increases on average by 13%. Notwithstanding the increase in the budget for preventive health care, the funds are reduced by on average 21% with every amendment and supplement to the approved budget in the course of the year. Hence we can conclude that the state, contrary to article 2.1 of the Treaty fails to provide the highest possible extent of financial and human resources in order to ensure progressive and full realization of the right to preventive health care of vulnerable categories of population, such as Roma people, women and children. Therefore the budget for the Program for health care of mothers and children is declining year-in and year out, with no funds from the budget allocated for additional patronage visits in marginalized communities with a special focus on the Roma people. As a result, Roma families receive 1.5 visits by the patronage nurses instead of 9 visits<sup>8</sup>. The health education activities aimed for Roma which were part of the Program for active health care of mothers and children in the period 2011 - 2015, were removed from the Program and the budget with the amendments of the Program in 2015. The Program for active health care of mothers and children for 2016<sup>9</sup> also does not have foreseen activities aimed for Roma communities in its budget.

Also, the activities from the Program for active health care for mothers and children in 2014 which pertain to antenatal checks and microbiological smear tests of pregnant Roma women who are recipients of social

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<sup>4</sup> In the period 2005-2011 for the realization of activities set out in the NAP for health care, the Government planned to set aside a total of EUR 4.231.919,00. The first allocation of funds was made in 2009, and by 2011 to total allocated in the budget of the Ministry of Health for that purpose amounted to a total of EUR 22.016,00 or 0,5 % of the overall budget.

<sup>5</sup> <http://esem.org.mk/pdf/Publikacii/2015/Alarm%2032.pdf>

<sup>6</sup> <http://esem.org.mk/pdf/Publikacii/2015/Alarm%2032.pdf>

<sup>7</sup> Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/29/33.

<sup>8</sup> The research conducted in the municipality of Shuto Orizari as part of the work in the field of monitoring in the community for the coverage of Roma mothers and children with the Programme for active health care of mothers and children, Association ESE and CDRIM. 2014.

<sup>9</sup> Program for active health care of mothers and children for 2016. Official Gazette of Republic of Macedonia, No. 2 from 8 January 2016.

assistance, unemployed or from family receiving minimum income were not realized because of absence of implementation mechanisms, and were thus removed from the Program for 2015<sup>10</sup>. At the end of 2015 the Ministry of health adopted measures according to which the co-payment for all the health services related to pregnancy will be covered from the State budget, thus these service are free of charge for the pregnant women.

The Program for cervical cancer screening envisages coverage of only 20% of the women who have been defined as a target adult group, but with implementation of this Program only 10 – 15% of women from the target group are covered annually. The Breast cancer screening program has not been implemented for four years (2011-2014), although it was approved and budgeted every year, the implementation of this Program started in mid 2015.

**The public health fund is not aligned with the entire economic policy and the economic development goals of the Republic of Macedonia.** In 2016, the Government of the Republic of Macedonia will set aside 15% more funds for health insurance of the unemployed than it did in 2014, which indicates that the planning of funds envisaged an increase in the number of unemployed.

**The public health budget is becoming increasingly more dependent on funds provided in the form of loans and donations.** The share of the funds provided from national/original sources for the purpose of financing health services is replaced each year by funds obtained as loans and donations, which significantly disturbs the financial stability of the health care system in the country and impacts the continuity in the provision of health services for citizens. In 2016, the amount that the Government of the Republic of Macedonia will provide for health protection and services in the central national budget in the form of loans will be 210% higher than in 2006. The 2016 funds provided through donations will exceed those in 2006 by 40%. Most of the funds obtained through loans<sup>11</sup> will be spent on construction and reconstruction of facilities, while those received as donation<sup>12</sup> will be used for a portion of the prevention programs. This leads to the conclusion that the modernization of the health infrastructure depends on loans, with a portion of the preventive health protection measures depends on donations.

Despite the continues increase in the capital expenditures, the expenditures for subsidies and transfers and foreign funds in the health sector, the health system in RM still remain undeveloped and the citizens are still facing problems to receive proper health services and health care.

The Ministry of Health of the RM in the period 2012 – 2016 realized activities and cost in amount of EUR 18.760.000, financed through the Dutch grant ORIO in the amount of EUR 7.428.800, the loan from the Council of Europe Development Bank and the central budget of the RM in amount of EUR 11.331.200 (as Macedonian government contribution to the ORIO project). The project is intended for expansion and modernization of the maternal and child health (MCH) system in Macedonia. The government of RM trough the Program for active health protection of mothers and children contributed to the ORIO project with MKD 1.100.000 in 2011 and MKD 2.590.000 in 2012.<sup>13</sup> Most of the funds used as contribution to the project were allocated for increased the capacities of the patronage nurses, education of the citizens for child health, early child development, etc. In the next four years, after signing the agreement for the ORIO project, the government cut all the measures used as contribution to the project. The project has four years delay in implementation of the activities prescribed in the application.<sup>14</sup> All the funds, according to the activities planned for the development phase in the application, were used for foreign consultancy services for conducting researches which are already

<sup>10</sup> "What do the experiences and data on (no) realization of the health component of the Strategy for Roma show 2005-2015?", evaluation initiative carried out by Roma SOS Prilep, KHAM Delchevo, HERA Skopje, LIL Skopje, CDRIM Skopje and RRC Skopje, March 2015, <http://romasosprilep.org/wp-content/publications/analizi/zdr-komponenta.pdf>.

<sup>11</sup> <http://www.esem.org.mk/pdf/Publikacii/2014/ESE%20Grant%20ORIO.pdf>

<sup>12</sup> The Global Fund to Fight HIV/AIDS, Malaria and Tuberculosis

<sup>13</sup> [www.esem.org.mk/pdf/Publikacii/Ostanati/Analiza%20od%20spoveden%20monitoring%20na%20implementacija%20i%20buget%20an%20Programata%20za%20aktivna%2033%20na%20majki%20i%20deca-2011.pdf](http://www.esem.org.mk/pdf/Publikacii/Ostanati/Analiza%20od%20spoveden%20monitoring%20na%20implementacija%20i%20buget%20an%20Programata%20za%20aktivna%2033%20na%20majki%20i%20deca-2011.pdf)

<sup>14</sup> November 19, 2012 (44.683 Euros); December 19, 2013 (99.600 Euros); September 04, 2014 (132.114 Euros);

available on the national level, instead of providing adequate health services. Thus, it is not clear why in 2014 the Ministry of Health requested increasing of the budget by EUR 136.246.867 (from EUR 18.760.000 to EUR 155.006.867), where the ORIO grant participation was increase by EUR 182.744 (from EUR 7.428.800 to EUR 7.611.544).

The Macedonian Government, through the document developed during the development phase of the ORIO (2012 – 2016), recognize the failure to achieve the European Commission notes for lack of effective decentralization in the health sector which negatively affect mothers and children indicators and deepening the health inequalities among the population. According to the Macedonian Government, Macedonia face high perinatal/infant mortality rates, lack of quality of outreach capacities, poverty, social exclusion. More precisely, through the ORIO project documents, the Macedonian health system has identify lot of capacity, financial and systematic problems, such as following:

#### **Capacity problems**

- Inefficiency in the community (patronage) nursing system in targeting mothers and children from socially vulnerable groups and imbalance in the service delivery of the patronage nurses in vulnerable communities especially rural population and Roma (not sufficient number of visits in the Roma communities during pregnancy and after delivery). Wide specter of services and lack of adequate transportation facilities;
- Lack of capacities among the mother and child health care providers and lack of specialized personal;
- Suboptimal level of effectiveness and efficiency in the operation of the health care;

#### **Financial problems**

- High level of social assistance and health care expenditures;
- Significantly lower health care expenditures as percentage of GDP than most of the countries in the region and EU;

#### **Systematic problems**

- Isolation of marginalized groups of people (especially rural population and Roma) to access mother and child health care services (7.5% of households with children are not covered by health insurance. Majority of Roma mothers and children are excluded from the health insurance system and cannot afford co-fund or pay the costs for antenatal examinations and transport.);
- Low and insufficient level of investments in the health sector;
- Poor utilization of primary and secondary care and overutilization of tertiary care.
- Poor management in the health system;
- Minorities and poor people are underserved because they do not know their way in the system of free health care and lack of appropriate help seeking behavior.
- High perinatal and infant mortality rate in rural and Roma communities (9.8 per 1.000 live births and 25% higher than average and 23% unattended births outside hospitals among Roma);
- Poor management practices and efficiency of the MCH programs
- Inadequate planning, budgeting and implementation of MCH programs
- Lack of health information and statistics for planning, budgeting, monitoring and reporting on MCH programs and service delivery in the area of immunization and home visiting;
- Low level of immunization coverage in marginalized communities (especially rural population and Roma) between 63 and 89% for different vaccines which is below the general population coverage and WHO standards;

Although the implementation of the ORIO grant has started since 2011 and funds has been spent for its implementation there is no improvement in regards to the main goals that were supposed to be achieved with

this grant. Moreover we are witnessing worsening of the situation regarding the health outcomes of mothers and child health and coverage of these groups with health services. This situation is in more details described under part “THE RIGHT TO HEALTH FROM A PERSPECTIVE OF VARIOUS VULNERABLE GROUPS”.

**Health data and statistic managed by the health institutions is with poor quality.** The health system lack updated and real time data, as a base for further development of the health policies and structuring the strategies in the health sector. There is no data segregated by ethnicity available. The allocation of the funds in the health budget is based on outdated health statistic and is priority driven. According to the research<sup>15</sup> carried out by Association ESE, notable is the trend of non-transparency and absence of accountability of the Ministry of health and most of the public health care institutions concerning their programmatic and financial operations. For example, in 2015 the Ministry of Health reached the bottom in terms of its pro-activity level. This means that in 2015, the Ministry did not release any information about its current work on its official website<sup>16</sup>. The Health Insurance Fund publishes 44% of the monitored information/documents<sup>17</sup> on its program and budget operation, which includes it in the category of partly proactively transparent public institutions<sup>18</sup>.

**The analysis shows that the health care intuitions on local level are more reactive transparent in comparison to the national level institutions.**<sup>19</sup> The level of proactive and reactive transparency of the institutions decrease subject of observation and interest is data on foreign aid. For example, the Ministry of Health of the Republic of Macedonia does not provide publicly available data and documents on the budgeted and realized activities and costs financed through the Dutch grant ORIO<sup>20</sup>, with an explanation that it does not have such data available. According to the official documentation, the Ministry of Health is the institution in charge of the project ORIO in RM and hence it is unclear how this ministry does not have information on the manner in which one quarter of the overall funds from foreign aid over the past 18 years have been poured in and out of its budget<sup>21</sup>. The Ministry of finance does not provide any information related to specific budget expenditures made trough the treasury system in the health sector. According to the Ministry of finance this type of data falls under category of classified data and the treasury must keep the secrecy of the data from the treasury system.

**There is unmet need for the financial assistance for care provided by the State and the amount provided is not sufficient to cover the costs for time allocated for care.**

There is no available data for the real extent of the unpaid care work done in the households for taking care of an adult person that is not able to take care of him/herself because they are chronically ill, disabled and/or elderly. Yet the data shows that the need for financial assistance for care from the State is increasing throughout the years, namely the number of beneficiaries of financial assistance for care provided by the Ministry of labor and social policies has increased from 19.640 beneficiaries in 2008 to 25.444 beneficiaries in 2012<sup>22</sup>. The care giving raises the issue of gender equality, representing greater burden on the women, since in most of the cases women are primary care givers<sup>23</sup>. Providing care has impact on the care givers’ ability to work and to financially contribute to the household, as well as on other spheres of his/hers life including social life,

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<sup>15</sup> <http://www.esem.org.mk/pdf/Publikaciji/2016/ESE%20Transparency.pdf> ; <http://esem.org.mk/pdf/Publikaciji/2016/reaktivna%202015.pdf> ; <http://esem.org.mk/pdf/Publikaciji/2016/reaktivna%20i%20proaktivna2015.pdf>

<sup>16</sup> The Ministry's website contains outdated versions of some of the monitored parameters.

<sup>17</sup> Work Strategy; Annual Work Program; Budget Calendar; Pre-budget Statement; Citizens Budget; Budget Proposal and Adopted Budget; draft and adopted supplementary Budget; Budget documents in open formats (xml or excel); Monthly Reports on Budget Execution; Mid - year Report on Budget Execution; Year - End Budget Report; Audit Report; data on the person responsible for mediating public information and List of Public Information.

<sup>18</sup> <http://www.esem.org.mk/pdf/Publikaciji/2016/ESE%20Transparency.pdf>

<sup>19</sup> <http://esem.org.mk/pdf/Publikaciji/2016/reaktivna%202015.pdf>

<sup>20</sup> What is happening with the money from the Dutch grant ORIO OPMO earmarked for improvement of health care for mothers and children in R. Macedonia, Association ESE, 2014, available in Macedonian: <http://esem.org.mk/en/pdf/Publikaciji/2014/ESE%20Grant%20ORIO.pdf>.

<sup>21</sup> In the period between 1996 to 2014 a total of EUR 33 773 706 was poured into the Budget of RM for the implementation of 44 project in the health care sector in general in the form of foreign aid. The total amount of funds that will be poured into the Budget of the Ministry of Health of RM for the implementation of the project ORIO accounts for 22% or almost one quarter of the total amount of foreign aid which RM has received over the past 18 years. available in Macedonian: <http://esem.org.mk/en/pdf/Publikaciji/2014/ESE%20Grant%20ORIO.pdf>.

<sup>22</sup> Source: Ministry of labor and social policy

<sup>23</sup> ESE’s Analysis on the unpaid care work for seriously ill or disabled adult in Roma households, 2015 (Pilot survey conducted in 19 Roma households that take care of an adult person that is not able to take care of him/herself because they are chronically ill, disabled and/or elderly)

community engagements and use of media. The unpaid care provided by a single care giver is worth an estimated 262.947,00 MK Denars per year, or approximately 21.912,00 MK Denars per month. Also the unpaid care work in the households is crucial because this work substitutes for the lack of availability of long term care capacities in the health system. State provides financial assistance for care of person in two extents: higher extent in amount of 4.348,00 MK Denars per month; and lower extent in amount of 3.846,00 MK Denars per month<sup>24</sup>. This amount is only sufficient to cover basic expenses for purchasing needed medicines and medical materials<sup>25</sup> but does not cover the costs for time allocated for care; neither provides funds for the households to hire external person/s or to accommodate the person that needs care in public or private institution for long term care. Also half of the households that take care for adult person that is not able to take care of him/herself do not receive the financial assistance from the State<sup>26</sup>, which indicates that there is unmet need regarding this issue.

## **2.2 THE RIGHT TO HEALTH FROM A PERSPECTIVE OF VARIOUS VULNERABLE GROUPS**

### **(THE HEALTH OF THE ROMA PEOPLE)**

Unfavorable socio-economic conditions in which Roma live contribute significantly to a less favourable health status and shorter life expectancy of Roma compared to the rest of the population. Monthly household income is significantly lower than that of other households and inflows largely come from social monetary assistance and from informal and unsteady work. Namely, slightly more than one quarter of Roma households live on monthly income below 3000 MKD<sup>27</sup>.

**In Macedonia currently there is no specific policy aimed for improvement of the health status and access to health services for Roma.** In 2014 the Government adopted National Strategy for Roma for 2014 – 2020<sup>28</sup> including health as one of the priority issues to be addressed. Yet until now the Government did not adopt the Action plan for health for Roma. Having in consideration that the previous Action plan for health ended in 2015, currently there is no valid Action plan for health in Macedonia.

**In Macedonia there is no publicly available health statistics (including morbidity and mortality) disaggregated by ethnicity.** All of the findings regarding health status, access to health care and related issues for Roma are based on the work and research conducted by the civil society organizations. The lack of official data represents serious obstacle for proper planning and implementation of activities aimed at improvement of Roma peoples' health as one of the most marginalized groups of the population.

**Roma are not adequately covered with specific measures of preventive health care intended for Roma communities and provided in the Programs of the Ministry of Health<sup>29</sup>.** Namely, Roma women in the municipality of Shuto Orizari<sup>30</sup> during pregnancy and after birth of a child are visited in their homes on average 1,5 times by a patronage (outreach) nurse instead of the mandatory nine visits<sup>31</sup>. The health education activities envisaged for Roma communities (educational workshops and educational materials) from 2011 to 2014 were not implemented for the Roma population in the municipalities of Shuto Orizari, Delchevo, Pehcevo,

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<sup>24</sup> ESE's Analysis on the unpaid care work for seriously ill or disabled adult in Roma households, 2015 (Pilot survey conducted in 19 Roma households that take care of an adult person that is not able to take care of him/herself because they are chronically ill, disabled and/or elderly)

<sup>25</sup> ibid

<sup>26</sup> ibid

<sup>27</sup> We are all human: Health care for all people regardless of their ethnicity, Association ESE and FOOM, 2014

<http://esem.org.mk/en/pdf/Publikacii/2014/We%20are%20all%20human.pdf>

<sup>28</sup> Available at: <http://www.mtsp.gov.mk/content/pdf/strategii/Strategija%20za%20Romite%20vo%20RM%202014-2020.pdf>

<sup>29</sup> Program for active health care of mothers and children, Program for general health check-ups of pupils and students and Program for cervical cancer screening.

<sup>30</sup> According to the official data, the majority of Roma people live in Skopje (23.475), 56% of whom are concentrated in the municipality of Shuto Orizari

<sup>31</sup> The research conducted in the municipality of Shuto Orizari under the work in the area of community monitoring for the purposes of coverage of Roma mothers and children with the Program for active health care of mothers and children. Association ESE and CDRIM. 2014.



Vinica, Gorche Petrov, Saray and Karposh<sup>32</sup>. All of it results in a below national average immunization coverage of Roma children at the age of 0 - 15. Coverage for different vaccines ranges from 35% - 100%<sup>33</sup>. Roma women are not to a sufficient extent covered with the Program for cervical cancer screening, namely only 19% of Roma women at the age of 24 – 60 have been covered with gynecologist examination with PAP test under the Program in the period 2012 – 2014<sup>34</sup>.

**Roma women face multiple barriers in access to gynecological health care on primary level, including distance, discriminatory practices and paying for services that are free of charge.** Concerning primary health care, the biggest problem is with access to gynecological health care for Roma women from the municipality of Shuto Orizari, since there is no clinic with a selected gynecologist in the municipality and the closest one is 10 km away. Due to the lack of financial means, it is a serious barrier to the realization of the right to gynecological health care. The second barrier is the occurrence of cases where gynecologists refuse to register Roma women as their patients, including pregnant women since they know that those women cannot pay for the examination<sup>35</sup>. In addition to the above, and above all due to the fact that Roma are poorly informed, it is more often the case with selected gynecologists to charge co-payment to Roma women, unlike other women, for services which are free and not subject to co-payment.<sup>36</sup>

All of the above results less frequent visits of Roma women to gynecologists for a regular preventive health check, and, a 19% of Roma women at the age of 18 plus have never been to a gynecologist<sup>37</sup>. Also, experience from the ground shows that in Shuto Orizari here is a trend of increased anomalies in new born babies, there are still born children, premature deliveries as well as serious and frequent vaginal infections of a high number of women in the municipality, including an increased number of deliveries at home without a presence of medically trained personnel<sup>38</sup>.

The data from ESE's survey<sup>39</sup> showed that the rate of identified changes from the performed PAP-tests among Roma women is very high. Namely, in 16,5 % of the Roma women who took the PAP-test through the activities from the Program for cervical cancer screening, changes were identified (positive findings with identified abnormal epithelial cells). In comparison from all performed PAP-tests in R. Macedonia according to the Program, abnormal epithelial cells were identified in 7%<sup>40</sup>. This data indicates that Roma women are at higher risk for occurrence of malignant changes of the cervix, mainly due to the fact that Roma women are not performing regular preventive check-ups on time, because of the distance from the gynecological office, lack of financial means and lack of knowledge and awareness.

**Roma people face multiple barriers in access to secondary and tertiary health care including distance, payments, lack of medical materials and inappropriate behavior from the health staff.** The specialist-consultative and in-patient services are part of secondary and tertiary health care in R. Macedonia. Regarding specialist-consultative care, one of the significant barriers from Roma is the physical accessibility of such services. Namely, the Polyclinic in the municipality of Shuto Orizari<sup>41</sup>, which is part of the health care center Skopje does not provide specialist-consultative health care and they only have the basic conditions for diagnostics, unlike polyclinics in the other municipalities which are under the health care center Skopje. In the

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<sup>32</sup>Coverage of Roma children with immunization and preventive health care services, problems and solutions. Association ESE, KHAM, CDRIM, LIL. 2014. <http://www.esem.org.mk/pdf/Sto%20rabotime/2014/1/Opfat%20na%20decata%20Rom%20so%20vakcinacija.pdf>.

<sup>33</sup>Ibid.

<sup>34</sup>Coverage of Roma women in the Program for cervical cancer screening in the period 2012-2014, 2015.

<http://www.esem.org.mk/en/pdf/Publikacii/2016/ESE%20Romki%20Skrining%20EN.pdf>

<sup>35</sup> Knowledge gained from field work by the Center for democratic development and initiatives– CDRIM and Roma Resource Center –RRC.

<sup>36</sup> We are all human: Health care for all people regardless of their ethnicity, Association ESE and FOOM, 2014

<http://esem.org.mk/en/pdf/Publikacii/2014/We%20are%20all%20human.pdf>.

<sup>37</sup> We are all human: Health care for all people regardless of their ethnicity, Association ESE and FOOM, 2014

<http://esem.org.mk/en/pdf/Publikacii/2014/We%20are%20all%20human.pdf>.

<sup>38</sup> Knowledge gained from field work by the Roma Resource Center (RRC) and the Center for Democratic Development and initiatives (CDRIM)

<sup>39</sup> Coverage of Roma women in the Program for cervical cancer screening in the period 2012-2014, 2015.

<http://www.esem.org.mk/en/pdf/Publikacii/2016/ESE%20Romki%20Skrining%20EN.pdf>

<sup>40</sup> Source: Institute for Public Health of Republic of Macedonia. Annual report for implementation of the Program for cervical cancer screening in 2013.

<sup>41</sup> According to official data, majority of Roma live in Skopje (23.475), of whom 56% are concentrated in the municipality of Shuto Orizari.



Bregalnica region there is a lack of specialist staff as relevant medical equipment and devices. Therefore, Roma people are exposed to additional costs. Roma people, compared to the rest of the population are less satisfied with the specialist-consultative services and in-patient services they receive. As an illustration, full satisfaction with the services received in specialist-consultative care is expressed by 49,2% of Roma patients, compared to 73,3% of the other patients, while full satisfaction with the in-patient services received is expressed by 33,3% of Roma compared to 68,2% of the other patients<sup>42</sup>. Despite the obligation laid down in the law stating that health care institutions providing in-patient services should have at their disposal the required medical materials paid by the Health Insurance Fund, there is nonetheless a practice of paucity of medical materials and equipment. There is a documented case where as a result of a lack of endoprosthesis (artificial shoulder joint) in public hospitals, the health of a Roma female patient has deteriorated seriously (Annex 1). In addition, Roma as patients are not sufficiently informed by the health care professionals about their health status, about the course of the treatment, measure taken etc. There are also registered cases of complaint that Roma patients have not been allowed access to their medical files<sup>43</sup>. Failure to provide quality health care services leads to serious deterioration of the health of patients, disability and death. Several cases have been documented which may illustrate the above: amputation and then a development of life threatening gangrene in an 8 years old child, death of a mother during the delivery for unknown reasons, and departure from the regular procedure of provision of health care services for Roma patients.<sup>44</sup> At all levels of health care there are cases of disrespect of cultural and traditional practices of Roma shown by health care professionals<sup>45</sup>. Due to their poor socio-economic status Roma people often cannot afford to pay the legally prescribed co-payment for the health services on secondary and tertiary level, as well as for obtaining the needed medicines. Namely 61,6% of Roma people in the past 12 months were not able to always purchase the prescribed medicines due to the lack of finances to pay the needed co-payment<sup>46</sup>.

**Roma people face discriminatory practices in the health care settings on all levels of health care and in the same time they are not reporting these practices to the relevant institutions.** According to the research<sup>47</sup> carried out by Association ESE, one third of Roma patients are exposed to rude treatment with disrespect shown by health care professionals when they visit a doctor specialist in specialist-consultative health care institutions and when they in patient services (hospital treatment). Health care of Roma women and their treatment by the selected gynecologist and by health care workers during the last pregnancy checks and at delivery also features rudeness and disrespectful treatment. Health care staff in the Polyclinic in Shuto Orizari often refuses to provide health care services to Roma with an explanation that their personal hygiene is at a low level without having taken into account the conditions in which some Roma people live<sup>48</sup>. Similarly, there are documented cases when patronage nurses ask the parents who living in poor housing conditions to take the baby out in the court yard for the check.<sup>49</sup> Roma people increasingly face refusal of hospital treatment by health care institutions, they are charged higher amounts for co-payment without a bill and their personal documents are retained due to failure to make the co-payment for hospital care<sup>50</sup>.

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<sup>42</sup> We are all human: Health care for all people regardless of their ethnicity, Association ESE and FOOM, 2014 <http://esem.org.mk/en/pdf/Publikacii/2014/We%20are%20all%20human.pdf>.

<sup>43</sup> Knowledge gained from filed work of NGO KHAM.

<sup>44</sup> The law in practice: Analysis of the challenges in legal protection of the right to health and healthcare of Roma from the practice of ROMA S.O.S. Prilep 2014, [http://romasosprilep.org/wp-content/publications/analizi/Analiza\\_Angliska.pdf](http://romasosprilep.org/wp-content/publications/analizi/Analiza_Angliska.pdf).

<sup>45</sup> Case documented by ROMA S.O.S Prilep with destruction of the body of a new born as medical waste without parental consent, [http://romasosprilep.org/wp-content/publications/analizi/Analiza\\_Angliska.pdf](http://romasosprilep.org/wp-content/publications/analizi/Analiza_Angliska.pdf).

<sup>46</sup> We are all human: Health care for all people regardless of their ethnicity, Association ESE and FOOM, 2014 <http://esem.org.mk/en/pdf/Publikacii/2014/We%20are%20all%20human.pdf>.

<sup>47</sup> ibid

<sup>48</sup> Knowledge gained from the field work by Roma Resource Center (RRC).

<sup>49</sup> Knowledge gained from the field work by the Center for democratic development and initiatives- CDRIM.

<sup>50</sup> Knowledge gained from the field work by Roma civil organizations (ROMA SOS, KHAM and Roma Resource Center).

**Unfortunately, Roma people do not report such discriminatory practices.** Namely in 2008 only two Roma persons filed complaints for discrimination in the area of health care with the Ombudsman, while in 2009, 2010, 2011 and 2012 only one Roma person filed a complaint<sup>51</sup>.

The unfavorable financial status of Roma people in combination with discriminatory practices is a serious obstacle to the realization of the right of access to medicines, in particular because Roma people are faced more frequently than the rest of the population with inability to find the prescribed drugs paid for by the Health Insurance Fund in pharmacies and they have to pay for them out of pocket<sup>52</sup>.

**The trend of minimal representation of the Roma people in the submission of petitions in the field of health insurance and protection to the Ombudsman continues in the period of 2012 to 2015.** Thus, in 2012 there were three (3) petitions submitted by Roma. In 2013, only one petition was submitted by a person of Roma ethnicity. 12 petitions submitted by Roma were registered in the following year of 2014, which is a year with a record number of Roma people who submitted petitions, and in 2015 there were four (4) petitions submitted by Roma.

Bearing in mind the difficulties which the Roma people are facing, the Association ESE, in collaboration with the Roma organizations 'Center for Democratic Development and Initiative – CDDI', Shuto Orizari; Roma Resource Center – RRC, Shuto Orizari and the NGO 'KHAM', Delchevo, has been providing since 2011 paralegal assistance and support to the local Roma population in order to protect their health rights (patient rights, healthcare rights, and health insurance right). From 2012 to 2015, a total number of 1,988 Romany were covered by such activities.<sup>53</sup>

#### **(WOMEN'S HEALTH)**

**Women in RM are insufficiently covered with health care services on primary level including primary gynecological health care and patronage nurse visits.** The main reason for this is the insufficient number of selected gynecologists in Primary health care and their uneven territorial distribution. In 2014 in RM there were only 138 gynecologists,<sup>54</sup>.According to the geographical standard of organization of a health care network in primary care, in R. Macedonia, there should be a total of 286 gynecologists on the basis of the number of women at the age of 14+, which means that there is a lack of 148 gynecologists. In 45 municipalities in RM there is no selected gynecologist and in 24 municipalities the number of selected gynecologists is insufficient<sup>55</sup>. As a result only 45,6% of women at the age of 14+ have a selected gynecologist<sup>56</sup>. According to ESE, in terms of antenatal care, 17% of women had less than four checks<sup>57</sup>during the first pregnancy, while 2% never had any checks at all<sup>58</sup>. The coverage of the women with patronage (outreach) nurse visits in their homes in the period during pregnancy and one year after the delivery is very low on national level. Namely, half of the women who gave birth in the last 24 months were never visited by patronage nurse in the period of pregnancy and after the delivery, and the average number of visits among other half of the women was 2,6 visits<sup>59</sup>. In the Program for active health care for mothers and children until 2015 it was foreseen that the women should be visited in their homes by patronage nurse two times during pregnancy and five times in the period of one year after the delivery.

<sup>51</sup> Data obtained through the Law on free access to information of public character (2008.-69; 2009.-72; 2010.-93; 2011.-115; and 2012.-166 submissions to the Ombudsman).

<sup>52</sup> Ibid.

<sup>53</sup> In 2012, help and support was provided for 587 Roma; in 2013 for 391 Roma; in 2014 for 500 Roma, and in 2015 for 520 Roma people.

<sup>54</sup> Health Insurance Fund of R. Macedonia, Annual report for 2014

<http://www.fzo.org.mk/WBStorage/Files/Godisen%20izvestaj%202014%20KONECEN.pdf>.

<sup>55</sup> Analysis,, In R. Macedonia policies are not in place to ensure a sufficient number of selected gynecologists and their even territorial distribution, Association ESE, 2013.

<sup>56</sup> Analysis of Association ESE based on „Annual report for 2014“ of the Health Insurance Fund of R. Macedonia.

<sup>57</sup> According to WHO recommendations for pregnancy checks are prescribed.

<sup>58</sup>, D-r Borjan Pavlovski, Assessment of the situation concerning sexual and reproductive health and the rights of the population in RM, ESE, 2012.

<http://www.esem.org.mk/pdf/Publikacii/Procenka%20na%20sostojбата%20po%20odnos%20na%20seksualното%20i%20reproduktivното%20zdravje%20i%20prava%20na%20naselenieto%20vo%20PM.pdf>.

<sup>59</sup> Ibid

In the Program for active health care for mothers and children for 2016 the Ministry of health has removed the provisions regarding the needed number of visits from patronage nurses in the period during pregnancy and after the delivery. At the moment there is no legal document which prescribes how many visits should be conducted by the patronage nurses in this period.

**Increase in infant mortality rate is noted in Macedonia in the period 2010 – 2014.** All of the above mentioned issues could be connected to the increase in infant mortality rate, namely the infant mortality rate in Macedonia in 2010 was 7.6 per 1000 live births and in 2014 was 9.9 per 1000 live births<sup>60</sup>, which is twice higher than the rates in the European Union countries<sup>61</sup>. Also perinatal mortality rate in Macedonia is very high and in 2014 was 14.3 per 1000 births<sup>62</sup> which is almost three times higher than the European Union countries<sup>63</sup>. There is no publicly available analysis or research conducted by the public institutions which will reveal the overall causes for this situation, and the State Statistical Office does not disclose the data regarding the cause of death of the infants and perinatal deaths.

**There is lack of coverage of women on national level with the Program for cervical cancer screening.** This is result to the above mentioned situation with the lack of gynecologists as well as due to the following reasons: lack of coordination and oversight mechanisms of the Program, lack of medical staff from other relevant fields (pathologists – cytologists, specialists in social medicine etc.), lack of activities for education and awareness raising among women for the need of regular gynecological check-up with PAP-test<sup>64</sup>. As a result of this only 11% of the women from target group were covered with the screening in 2013<sup>65</sup>

**The degree of practicing contraception is low amongst the women in their reproductive period and abortion is still used as a method of family planning, in particular by married women.** According to ESE<sup>66</sup>, 6% of women in their reproductive period over the past 12 months have used oral hormonal contraception; 2% have used barrier means; 14% traditional contraception (interrupted intercourse and calendar method), and most of them have used a condom (22%). This situation is a result of poorly informed women on individual means of contraception, fear of harmful consequences to their health and objections by the partner. In addition, not a single means for oral hormonal contraception is on the positive list of drugs funded by Health insurance Fund, or in other words women have to pay for the full amount for this. As regards abortion, according to ESE<sup>67</sup>, 15% of women in their reproductive period have had a minimum of one abortion in their life, or on average every women has had two abortions. The most frequently mentioned reasons for abortion are the socio-economic conditions. Notable is the lack of family planning by spouses, or 21% of women who have given birth say that their first child was not planned.

## **(HEALTH OF PERSONS LIVING WITH HIV)**

**People who live with HIV cannot exercise their right to health equally and without being discriminated.** According to the needs assessment of persons living with HIV<sup>68</sup>, one quarter have reported that they have been refused health care services. Equal number of people has had their HIV status revealed in the presence of other people without their consent. The most frequent violators of the rights of these individuals are employees in health care institutions with serious cases of insulting and unprofessional attitude and

<sup>60</sup> State Statistical Office. Monthly statistical bulletin of the Republic of Macedonia. 2016. [http://www.stat.gov.mk/Publikacii/1.2.16.02\\_en.pdf](http://www.stat.gov.mk/Publikacii/1.2.16.02_en.pdf)

<sup>61</sup> Source: WHO Regional office for Europe. Health for all data base. <http://data.euro.who.int/hfad/>

<sup>62</sup> State Statistical Office. Statistical Year Book. 2015. <http://www.stat.gov.mk/Publikacii/PDFSG2015/03-Naselenie-Population.pdf>

<sup>63</sup> Source: WHO Regional office for Europe. Health for all data base. <http://data.euro.who.int/hfad/>

<sup>64</sup> ESE. Recommendations for improvement of the implementation of the Program for cervical cancer screening. 2015. <http://www.esem.org.mk/pdf/Publikacii/2015/Preporaki%20Skining%20kancer.pdf>

<sup>65</sup> Institute for Public Health of Republic of Macedonia. Annual report for implementation of the Program for cervical cancer screening in 2013.

<sup>66</sup> ESE, D-r Borjan Pavlovski, Assessment of the situation concerning sexual and reproductive health and the rights of the population in RM, 2012.

<http://www.esem.org.mk/pdf/Publikacii/Проценка%20на%20состојбата%20по%20однос%20на%20сексуалното%20и%20репродуктивното%20здравје%20и%20права%20на%20населението%20во%20РМ.pdf>.

<sup>67</sup> Ibid.

<sup>68</sup> Association HERA and Association of persons living with HIV, Stronger Together, available at: [http://hera.org.mk/wp-content/uploads/2015/02/Istrazuvanje\\_HIV-2014.pdf](http://hera.org.mk/wp-content/uploads/2015/02/Istrazuvanje_HIV-2014.pdf)

discrimination. Issues related to stigma and discrimination, and the specific needs of persons living with HIV have not been included in the official curriculum for the continuous training of healthcare workers.<sup>69</sup>

**People living with HIV do not use the legal mechanisms for protection of their rights due to their inefficiency, fear of disclosure of their health status, red tape procedures and distrust in that the result of the procedure will be in their favor<sup>70</sup>.** Such results are not surprising if we take into account that the Commission for protection against discrimination in the four years of its existence has proceeded in two cases of discrimination on the basis of a health status (HIV). In the first case a negative opinion was issued<sup>71</sup>, and the second case is still pending. In both cases the legal deadline for proceedings has been broken. The situation is not different with the other responsible authorities for proceedings in cases of violation of health care rights. For example in the case of A.K. vs. PHI General Hospital Ohrid, the State sanitary and health inspectorate found when proceeding on a complaint that it was not a case of discrimination<sup>72</sup>, while the Ombudsman found that there was discrimination on the basis of a health status (HIV)<sup>73</sup>. Such lack of coordination between the institutions contributes for an ever greater distrust and discouragement of the persons living with HIV to seek legal protection of their rights.

#### **(HEALTH OF PEOPLE WHO USE DRUGS)**

**Availability of treatment for opioid drug addiction in the Republic of Macedonia is insufficient and people who use drugs often face barriers in accessing the substitution programs.** Geographical and physical barriers are most prominent and especially affect member of marginalized populations, such as people who use drugs living with low income and ethnic minorities<sup>74</sup>.

Substitution treatment covered by the Health Insurance Fund is highly centralized and only available at three locations in Skopje. Thus, drug users who live across all municipalities in Skopje do not have easy and safe access to this treatment. The access to substitution treatment for people who use drugs in Macedonia is further impaired by the difficulties in obtaining a referral from primary health care physician, which is obligatory for enrolment in the treatment programs. Namely when the selected physician finds out that the person is a drug user, he/she refuses to receive him as his/her patient. The most frequent excuse is that there are no more patient vacancies despite the fact that under the legislation in force in Macedonia there is no limit on the number of patients that can be registered with selected practitioners. **People who use drugs frequently face discrimination and refusal of care by primary health care physicians, despite ethical and regulatory obligations.**

#### **(HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITY)**

**Certain age group of people with intellectual disability is faced with limited access to free health care, treatment and medication.** Namely, the Law on Health Insurance stipulates the exemption from participation in the use of health care services only for children, i.e. for people with intellectual disability up to the age of 26, but not afterwards. Specialized health services, programs and facilities for children and people with intellectual disabilities are provided only on national level<sup>75</sup>.

<sup>69</sup> HERA, HIV Prevention Report Card among Girls and Young Women, 2012, available at: <http://hera.org.mk/?p=2362>.

<sup>70</sup> [http://hera.org.mk/wp-content/uploads/2015/02/Istrazuvanje\\_HIV-2014.pdf](http://hera.org.mk/wp-content/uploads/2015/02/Istrazuvanje_HIV-2014.pdf).

<sup>71</sup> Opinion of the Commission for protection against discrimination AS vs PHI Anchevski Laser Labno. 07-483/6 од 27.03.2013.

<sup>72</sup> Correspondence from the State sanitary and health inspectorate no. 16-2100/4 dated 09.12.2014.

<sup>73</sup> Opinion of Ombudsman no. 3512/14 dated 12.12.2014.

<sup>74</sup> HOPS 2011, Improving access to social and health care for Roma who use drugs. Skopje: Healthy Options Project Skopje.

<sup>75</sup> Early detection, assessment and treatment for the children with mental disability is done in the developmental counseling offices in Skopje and Bitola and the Institute for mental health of children and youth „Mladost“ in Skopje. The Institute for medical rehabilitation in Skopje provides physical rehabilitation for the people with mental disability. The Institute for rehabilitation of the hearing, speech and voice (Skopje and Bitola) conducts rehabilitation programs also for children with mental disability at preschool and school age.

**People with intellectual disability and their parents are often faced with inadequate attitude by the medical staff,** especially in the specialist consultative health care and hospital facilities. 57% of the interviewed people with intellectual disability and their parents are dissatisfied from the health services.<sup>76</sup>

**The system for assessing the specific needs of the people with physical and intellectual disability is obsolete and insufficiently developed.** The assessment (categorization) is carried out by several regional committees and furthermore, the findings and the opinion from the assessment do not include the list of needs and recommendations for further treatment of these people.

**The rulebook on the realization of the right to mobility is not applicable to individuals with intellectual disability and it imposes a use of a “wheelchair” as a precondition for the exercise of this right.** Namely, individuals with severe, deep and combined intellectual disability, although they do not use a wheelchair, are not in a position to move around independently and without an escort.

#### **(HEALTH OF VICTIMS OF TRAFICKING IN HUMAN BEINGS)**

**The state does not provide financial and institutional support for ensuring the health care for the victims of human trafficking.** According to the data from Open Gate<sup>77</sup> in the period from 2005-2015, there were 153 identified individuals as victims of human trafficking, whereby 94 individuals used the services in the state shelter for victims of human trafficking. In most of the cases, the victims were placed in the shelter on long-termed basis and needed the following health services: medical and gynecological examinations, laboratory tests, testing for HIV/AIDS and Hepatitis A, B and C, TBC, dental examination etc. The medical examinations were conducted both in public and private medical facilities, depending whether the victims had health insurance. It is worth noting that the Ministry of Labor and Social Policy provides only 17% of the funds for the operation of the shelter, and therefore given the lack of funding, the health care of the victims of human trafficking is provided only by Open Gate.

Some of the individuals who are victims of human trafficking, although they possess health insurance coverage<sup>78</sup>, still they face problems in the exercising of their rights to health because they are placed in the shelter in Skopje, and their family doctors are most often from other towns or others do not have their family doctors. Therefore, they are having problems with the supply of medicines and the use of higher levels of health care.

#### **(HEALTH OF PEOPLE WITH RARE DISEASES)**

**The families in R. Macedonia facing problems with diagnosing of rare diseases (lack of reagents, technology) and the state do not cover the costs of diagnosing abroad.** There is poorly developed awareness of the general public and expert community of the significance of rare diseases and the impact of rare diseases on health and quality of life. For the first time in 2009 a Program for rare diseases was passed under which care was provided for the needs of only three patients. In 2015, with the amendments to the Law on excise taxes<sup>79</sup>, funds for diagnosis and treatment through the Program of rare diseases are obtained from the taxes from tobacco products.

**There are no specific criteria for the implementation of this program and rare cancers are excluded from the program. Also, there is lack of transparency and oversight mechanisms for the implementation of the program.** Patients don't have information how to be included in the Register, how to obtain treatment through the program and how to obtain other necessities (orthopedic devices, special food, supplements, and etc.) for their well being.

At the Ministry of health since 2015, there is a patient register for rare diseases and 240 patients were registered until May, 2016. The associations of patients for rare diseases are not involved in the process of the registering and the implementation of the program. There is also concern about parallel import of drugs (it is

<sup>76</sup> Report from the survey carried out by RCPLIP- PORAKA, available at [www.poraka.org.mk](http://www.poraka.org.mk).

<sup>77</sup> <http://www.lastrada.org.mk/userfiles//Analiza%20Otvorena%20Porta%20%28finalna%2025%2009%202012%2013%281%29.pdf>.

<sup>78</sup> Law on Health Insurance, Official Gazette No.25/2000, Article 5, paragraph 10 „ People placed in an institution for social protection (for institutional and non-institutional care) have mandatory health insurance“.

<sup>79</sup> Under the Law on Excise taxes one Macedonian denar from each packet of cigarettes shall go to the Rare Diseases Program.

done without certificate of origin or certificate of quality about the drugs, the only criteria on the tender for drugs is price, which in the case of rare diseases is not applicable, the drugs are expensive and most of them need special conditions for transport and safekeeping).

**There is no adopted National Plan for rare diseases, which is needed for organization of all segments in the approach to rare diseases.** Regarding social and health services, rare disease patients are not acknowledged as a separate group, which is needed since these diseases are complex and challenging for management.

In addition, other than the special child allowance for children with special needs there are no other measures of social care for making the lives of these people easier and better. In a high number of families one of the parents is forced to leave his/her job to be able to care for the child suffering from a rare disease. There are no care options for adult patients if care is warranted.

### 2.3 PROTECTION OF PATIENT RIGHTS

**All mechanisms for patient's rights protection introduced with the Law on Patient Rights Protection from 2008 have not yet been established and therefore one of the basic requirements for unimpeded functioning of the patients rights protection system is not yet fulfilled.** The rights of the patient and their protection are governed by the Law on Patient Rights Protection<sup>80</sup>. This law governs the patient rights protection when using healthcare, the rights and obligations of the patients, the rights and obligations of the healthcare institutions and the healthcare workers and collaborators, the municipalities and health insurance fund in the protection of the rights of the patients, the patient rights protection procedure, as well as the supervision over the application of the law. The patient rights protection should provide quality and continuous healthcare, suited to the individual needs of the patient, without any psychological or physical abuse, with complete respect to the dignity of the person and in the best interest of the patient.

Multiple institutions and bodies care to implement and protect the patient rights, amongst which: The Committee for Promoting Patient Right in the Municipality; the State Committee for Promoting Patient Rights; the counselors for patient rights protection and the Office in an inpatient healthcare facility; other healthcare institutions – units in the healthcare facility; the Ministry of Health – person for patient rights protection; the Health Insurance Fund; the State Sanitary and Health Inspectorate (SSHI) and the courts. Bearing in mind that the existence of the above-mentioned bodies is a prerequisite for the patient rights protection, their establishment is of key importance. According to the data of the SSHI, as of 2014 there were no municipal Committees for Patient Rights Protection formed in 36 municipalities (out of 84 total), while the committees formed in the rest of the municipalities are not active. There are established offices in 29 regional units of HIF and in Skopje, for professional aid for the insured patients to realize the protection of their rights from the health insurance. There still is no person appointed for patient rights protection in the Ministry of Health and a State Committee for Patient Rights Promotion has still not been established.

Regarding the fulfillment of the legal commitments regarding the patient rights protection, according to SSHI<sup>81</sup>, these commitments have been generally fulfilled (the period following the adoption of the Law as of 2014). In other words, the text of the law is prominently placed in the healthcare institutions, the patients are familiar with their rights, and the institutions keep record of the complaints and petitions submitted by the patients. According to the annual reports<sup>82</sup> of SSHI for the period 2009-2014, this body carries out an average of 120 irregular surveillances annually, which means that an exactly same average number of petitions are submitted annually by the patients. The number of petitions regarding the work of inpatient healthcare facilities forefronts<sup>83</sup> those submitted with regard to healthcare institutions that do not accommodate patients. The list

<sup>80</sup> Official Gazette of RM no. 82/2008, 12/2009 and 53/2011.

<sup>81</sup> Inspection surveillance over the implementation of the Law on Patient Rights Protection is carried out by the **State Sanitary and Health Inspectorate – SSHI** via the state sanitary and health inspectors, who, in case of injury, and after a submitted request, are authorized to order the institution and the healthcare worker to take appropriate measures and actions depending on the type of injury of the right. This institution carries out regular and extraordinary surveillance (surveillance upon a submitted petition), as well as surveillance regarding an established record of complaints and proceeding/responding to them in the period of 15 days.

<sup>82</sup> <http://zdravstvo.gov.mk/izvestai-od-dszi/>.

<sup>83</sup> 536 in inpatient units, as opposed to 375 in institutions which do not accommodate patients.



of issues because of which the citizens have submitted petitions is long, amongst which: dissatisfaction with the treatment and surgical intervention performed; dissatisfaction with the treatment and the attitude of the doctor or other healthcare worker; incorrect behavior of the healthcare workers; failure to provide healthcare, failure to perform medical intervention, or examination by a specialist; reckless and unprofessional work by a doctor; preventing insight into a file and photocopies of documents of the health documentation; unrealized examinations or diagnostic intervention scheduled via “my term”; dissatisfaction with the treatment results and additionally occurred complications; dissatisfaction with the postponed surgical intervention due to insufficient medical expendables and insufficient reagents for pathophysiological investigation; charging for a medical service which is free or inappropriate charging for participation for performed medical service; dissatisfaction with the quality of performed dental services; dissatisfaction with untimely delivery of results of a diagnostic procedure performed and untimely and incomplete delivery of medical documentation; no response to requests for conciliatory examination and dissatisfaction with a negative conciliatory opinion for treatment abroad; non-refunded funds for drugs; a longer period required for scheduling an examination for the waiting list; dysfunctional prosthetic aids; untimely and incomplete delivery of medical documentation; failure on part of health workers to adhere to the working hours; unprofessional and untimely provision of emergency medical aid. Dissatisfaction with the work conditions, obsolescence of the apparatuses and the waiting time for the provided healthcare, etc.

**Health Insurance Fund and Ministry of Health are acting untimely, unreliable and even obstructing patient’s rights protection. Even more they are not acting upon the Administrative court decisions.** One of the pointers for the injuries and the violations of the healthcare rights is the data provided by the Ombudsman. Namely, if we are to compare the total number of submitted petitions<sup>84</sup> regarding healthcare and insurance in the period 2012-2015, we can notice a trend of constant decrease of the number of petitions submitted. The number of petitions is lowest in 2015, which is 31% lower than in 2014, and 210% lower than in 2012. One of the key problems listed is the untimely processing of requests submitted by the citizens by the Health Insurance Fund and the Ministry of Health. In some cases, the citizens wait for years for their cases to be resolved. One piece of information<sup>85</sup> composed by the Ombudsman regarding the work of the regional units of HIFM for 2014 points out to multiple reasons for such treatment. Namely, the dissatisfaction of the citizens with the work of HIFM is due to: long decision-making procedures, especially for deciding on complaints submitted to the Ministry of Health; unreliability regarding the application of the regulation when deciding on the requests of the citizens, due to the frequent changes of and additions to the matter in this field; inappropriate communication with the Ministry of Health regarding the delivery of the required documentation and papers for deciding on the cases, and that is partially the result of technical problems. The reports<sup>86</sup> of the Ombudsman determine that HIFM, as a first instance body, oftentimes does not act with regard to carrying out the decisions of the Ministry of Health and the Administrative Court, and instead of acting on their directions, it once more adopts an act in which they decide as they previously have. There have also been noted cases regarding the actions by the Ministry of Health<sup>87</sup> of untimely actions within the legally determined deadline, but also far greater violations, such as obstructing the citizens in the efficient decision-making on their lawsuits in such that it does not deliver the papers to the Administrative Court. Although the court issues verdicts in favor of the citizens, second-instance reviews and decision-making procedures end in adopting decisions which reject the requests of the citizens and the latter are forced to prove that their request for rights in the field of healthcare and insurance is grounded.

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<sup>84</sup> A total of 166 petitions in this field in 2012; a total of 128 in 2013; a total of 125 in 2014, and a total of 79 petitions submitted in 2015

<sup>85</sup> <http://ombudsman.mk/upload/documents/2015/Predmetno%20rabenje-Infomacii/Infomacija%20zdravstvo-2015.pdf>

<sup>86</sup> [http://ombudsman.mk/MK/godishni\\_izvestai.aspx](http://ombudsman.mk/MK/godishni_izvestai.aspx)

<sup>87</sup> [http://ombudsman.mk/upload/Godisni%20izvestai/GI-2015/GI\\_2015-za\\_pecat.pdf](http://ombudsman.mk/upload/Godisni%20izvestai/GI-2015/GI_2015-za_pecat.pdf) (pages 49 and 50)

Ongoing negative practices of violations of the right to health can be illustrated with two individual cases<sup>88</sup> supported by the Association ESE upon the referral made by the Roma CSO's KHAM, Delcevo. In the first case, the alleged perpetrators are health care professionals from two state clinic hospitals, and in the second case perpetrators are members of the Board of the directors of the Health Insurance Fund (HIF). In both cases, following violation of patient's rights were identified: right to the highest attainable standard of health, timely medical treatment, right to obtain timely and adequate information, right to avoid unnecessary suffering and pain and right to effective remedy (Strategic cases are in details described in Annex 1).

### **3. RIGHT TO GENDER EQUALITY AND LEGAL PROTECTION OF WOMEN VICTIMS OF VIOLENCE AND DISCRIMINATION (Article 3)**

This part of the report focuses on assessing the implementation of Article 3 from ICESCR, in relation to the provided legal protection of different categories of women victims of violence and discrimination: domestic violence, trafficking in human beings, sex work and psychological and sexual violence at work place. In this regard, it is important to notice that all the findings presented within this report were assessed through the position of women, with the exemption of the part about harassment where the findings are general and are concerning both women and men. The subject of assessment is the formal system for protection of different categories of women victims of gender based violence and its implementation in practice.

#### **3.1 MECHANISMS FOR PROTECTION AGAINST DISCRIMINATION AND UNEQUAL TREATMENT**

**The experience of the Commission for protection against discrimination shows that there has been failure to apply the principle shifting burden of proof to the potential discriminator** although the Law on protection against discrimination<sup>89</sup> provides for its application. The most frequent procedure of producing evidence before the commission boils down to the word of the petitioner (the victim) against the word of the alleged discriminator. This practice is often time discouraging for the victims who seek protection against discrimination, and have no available evidence to present, since it is the discriminator who has the evidence. In addition to the procedure administered by the Commission for protection against discrimination, discriminated persons may also file a petition with a court of competent jurisdiction for protection against discrimination. **The established mechanism for protection of the right to equal treatment of genders in the Law on equal opportunities for men and women<sup>90</sup>, or „equal opportunities advocate,, is inefficient and is not applied in practice.**

#### **3.2 VIOLENCE AGAINST WOMEN**

##### **(DOMESTIC VIOLENCE)**

**The new adopted Law on prevention, combating and protection against domestic violence<sup>91</sup> cannot assure efficient and proper implementation in practice.**

The law and the bylaws have failed to introduce significant changes in terms of the number/type of measures of protection and temporary measures of protection. A new protection measure has been introduced – economic empowerment of the victim by way of her active involvement in the labour market. This measure falls into a group of active employment measures of Government and intended for specific target groups which until the adoption of this law was implemented as a project activity. Whether and to which extent such measures help the victims has not as yet been ascertained.

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<sup>88</sup> Association ESE providing legal, financial and technical support as regard the court procedure in front of the Basic Court Skopje (in the first case), and the administrative and court procedure in front of Health Insurance Fund and Administrative court Skopje (in the second case).

<sup>89</sup> Law on protection against discrimination, Official Gazette of RM, no.50/2010.

<sup>90</sup> Law on equal opportunities for men and women, Official Gazette of RM no. 6/2012.

<sup>91</sup> Law on prevention, combating and protection against domestic violence, Official gazette of RM, no.138/14 и 33/2015

Also, in the procedure of assessing the needs of the victim carried out by the team of experts from Centers for social care, securing consent of the victim for taking protection measures was introduced, which presented an unnecessary administrative burden in this procedure in light of the knowledge that the purpose of such measures is unconditional help offered to the victims through mandatory implementation of such measure.

**One of the biggest shortcomings is the enforcement of laws, particularly when we speak about the treatment of domestic violence cases by the Centers for social care.** Recently the Basic court brought a judgment for a crime of failure to exercise due diligence in the performance of duties arising from the service. As a result of their negligent actions a triple murder of family members of the victim was committed by her ex husband. There are frequent cases when social care workers cannot make a judgment about who is a primary offender and they respond to a report by those perpetrating violent acts while the victims are put in a position to prove that they are not the “villains”. On the other hand, the accommodation of victims of domestic violence is still not available to a high number of victims (poor capacities and coverage of the territory of the country), nor is it administered in line with a predefined set of standards and criteria. The new law envisages that the Center for victims of domestic violence “may”, though it is under “no obligation” to provide psycho-social intervention and treatment of the accommodated victim.

**Legally prescribed urgent deadlines of imposing and issuing temporary measures of protection are not respected by the responsible institutions.** There are changes also in terms of imposing temporary measures of protection. The solutions in the new law provide in the event of a serious threat to the life and health of family members, instead of urgent action within three days from the day of receipt of petition, as has hitherto been the case, that the court shall decide within 24 hours without a hearing on the imposition of measures on the basis of a finding issued by an expert and on the basis of an opinion provided by Centers for social care and at a proposal of the Ministry of interior concerning the measure – removal of the offender from the home and a restraining order. Given the track record of inefficient operation of Centers for social care as well as the fact that the law does not set a deadline within which they must make an assessment and prepare a report on their finding and issue an opinion, there is a high likelihood that the implementation of this provision of the law shall not bring about any change. Then again, the Ministry of interior shall attach to the proposal for imposition of the measure of removal from the home a police report on the assessment made of the risk to the live and physical integrity as well as the risk of repeat of the act of violence, which implies that they should receive education which unfortunately has not been put in place on a systemic and continuous basis. Also, it is important to mention that the decision of the court within 24 hours will be contingent upon whether there is a judge on duty in the afternoon and at weekends, as system not yet introduced and not yet functioning in our judiciary. Hence the abidance by this legal obligation for urgent action within 24 hours is unrealistic and unattainable.

The data received from the operations of ESE and the analysis carried out<sup>92</sup> show that the court fails to respect the urgent deadlines set in the law to impose measure, which is an additional problem which has not been addressed with the new solutions laid down in the law. Namely, the court has acted in line with the deadline of 7 days for setting a date for a hearing only in 46,7% of petitions for imposition of temporary measures of protection against domestic violence.

The data on protection of victims of violence under the Criminal code, collected by the USAID’s Women’s Legal Protection Project show certain weaknesses, which must be thoroughly examined and analyzed. **Namely, the number of criminal charges filed with reference to acts of violence against women between 2012 - 2014 shows a trend of increase<sup>93</sup>, unlike the trend of indictments<sup>94</sup> which is not consistent with the number of**

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<sup>92</sup> Analysis of courts actions when imposing temporary measures of protection, Association ESE, 2014. The analysis covered 84 court cases in which temporary measures of protection were issued, and 168 court hearings in ten courts in the towns of Bitola, Kumanovo, Shtip, Strumica, Veles, Radovish, Delchevo, Debar, Gostivar and Tetovo.

<sup>93</sup>Data on thirteen of the total of 22 Public prosecutor offices in RM were analyzed. In 2012 a total of 640 criminal charges were filed; 2013-685, and in 2014 the number of criminal charges is 843.

**criminal charges.** The trend of submitted petition for criminal prosecution filed is disconcerting (bodily injury which is the most frequent grounds for sanctioning domestic violence) over the same period is on the decrease<sup>95</sup>. This even more so given that out of the 169 petitions filed in 2014, 117 were withdrawn by the victim.

**There is a still trend of imposition of milder punishments than those provided in the law through the institute of „issuing milder sentences“.** Data received from criminal courts<sup>96</sup> on cases of violence against women for the period 2012-2015 support this finding. Namely, of the total of 751 judgments, 76% were convictions, 7,3% acquittals, and 16,7% were overturned. Disconcerting is the fact that of the total number of convictions only in 28.8% of the cases the punishment was a sentence of imprisonment imposed by the court, while in 9.2% the offender were punished with a monetary fine, and in 62% of the cases alternative measures were issued with a conditional judgment .

**Despite the determined legal obligation and allocated financial resources, Republic of Macedonia didn't succeed to establish and enhance the system of data collection** to ensure that data are disaggregated by type of violence and by the relationship of the perpetrator to the victim and ensure that data are available to the public” . Namely, the most recent attempt to overcome this problem by the state was made with the activities of the UN Joint Program of “Strengthening National Capacities to Prevent Domestic Violence 2008-2011”. It is alarming that all funds for the purpose of establishment of the “unified central data collection system for monitoring incidences and trends of domestic violence”<sup>97</sup> are spent and there is no such system established in practice. Moreover, the situation with the collection of data is the same as it was in 2008 i.e. prior to the adoption of the first National Strategy. Furthermore, UN agencies have spent 120.000 EUR for this purpose without even imposing the obligation for data collection for all relevant institutions. This fact can be confirmed with the second National Strategy 2012-2015, where it is noted that only Ministry of Labor and Social Policy and Ministry of Interior are collecting data on domestic violence cases. Moreover, 72.000 EUR were allocated for the “development of central database software application and installment within all data collection instances”<sup>98</sup> which was not established at all.

#### **(SEX WORK)**

**The regulation on sexual work and even more the restrictive policies exercised by the bodies in charge of enforcement of the laws contribute to the existence and maintenance of systemic discrimination, violence and exploitation of sex workers. Incrimination of sex work of one's free will pushes sex workers underground, which results in a limited access to health, social and legal aid and significantly reduces the chances to identify the victims of trafficking in human beings.**

Sexual work in the Republic of Macedonia is regulated as an offence against public peace and order and it is subject to a fine of EUR 600-800 in Macedonian denar counter value. Intermediation, or organization of sexual work is sanctioned in line with article 191 of the Criminal Code, as a crime of „Intermediation in prostitution“. This provision is in practice enforced most frequently to initiate criminal prosecution of sexual workers who for safety reasons in most cases work in together (two or more women), and in particular those who work indoors (apartments ). Experience has shown that when several sexual workers work in shared premises of their own will and autonomously, one is accused of solicitation for prostitution while the others are invited to stand witness. This provision in the law results in incrimination of sexual work, marginalization and disrespect of the rights of sex workers and in turn legal insecurity for them.

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<sup>94</sup> In 2012 429 indictments were issued, in 2013-436, and 2014-315.

<sup>95</sup> In 2012 a total of 218 criminal prosecution proposals were filed, 2013-199, and in 2014-169.

<sup>96</sup> Data were made available by 18 of the total of 27 basic courts in the country.

<sup>97</sup> UN Joint Program Strengthening National Capacities to Prevent Domestic Violence, Output 2.

<sup>98</sup> UN Program Budget, Output 2,Item 3.

On the other hand, the National HIV strategy for 2012-2016 has identified sex workers as a group of people exhibiting risky behavior on which specific interventions should focus.<sup>99</sup> The strategy recognizes the associated stigma and discrimination of sex workers as a significant factor that should be taken into account when designing and implementing activities. Therefore one of the strategic objectives is the strengthening and support of sex workers and their inclusion in the processes of planning, implementation and evaluation of policies and services intended to serve them. Also, sensitization of social and health care workers is needed, as well as of the media and members of the police force so that a supportive environment can be created to ensure effective prevention of HIV/AIDS/STD spread amongst sex workers.

### **(TRAFFICKING IN HUMAN BEINGS)**

Trafficking in human beings was incriminated in February, 2002 with the introduction of article 418-a „trafficking in human beings“ in the Criminal Code. With the subsequent changes of the Criminal code a criminal liability was introduced for legal entities engaged in trafficking in persons, a new stand alone article on trafficking in children and the maximum penalty for trafficking in persons was raised.<sup>100</sup> The Law on Criminal procedure passed in 2010 regulates the rights of victims in Chapter V with the title „Victim, injured and private accuser“ (article 53 to 56). Under this law, as victim of a crime which is subject to a penalty of imprisonment of a minimum of four years (as is trafficking in human beings) has a right to a legal representative provided by the state when making a statement if there is a serious physical and psychological damage or consequences of the crime, and the victim is also entitled to a compensation of tangible and intangible damage from the state fund under the conditions and in a manner defined in a separate law provided that the damage cannot be compensated by the accused.

**Although there are cases where victims of trafficking have received a ruling to the effect that they are entitled to compensation, it cannot be enforced because the offenders do not own property or have any money.** At present, this method of compensation (through a state fund) is available only to minors who are victims of trafficking. Nonetheless, the functionality of this option provided in the law has been brought into question. In case of adult victims of trafficking the compensation by the state will be postponed until the moment of adoption of the Law on state fund.<sup>101</sup>

### **The expert witness testimony needed for the compensation procedure is not covered from the state budget.**

Namely, under the provisions of the new Law on criminal procedure which pertain to a compensation to damage of property, the authorized person (victim, legal representative, power of attorney holder) shall file or have prepared an expert witness testimony by a neuro-psychiatrist and bear the costs, which was not the case under the old Law on criminal procedure. Namely, under the provisions of the old law, the expert witness testimony was covered from the budget of Republic of Macedonia.

Our legislation does not contain a specific provision which pertains to the impunity of victims of trafficking for their involvement in illegal activities including illegal migration, to the extent where they are forced to engage. There are no instructions for public prosecutors concerning the steps to be taken when prosecuting persons who might be victims of trafficking.

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<sup>99</sup> Government of Republic of Macedonia, national HIV strategy 2012-2016.

<sup>100</sup> At present, Chapter XXXIV of CC entitled „Crimes against humanity and international law “ contains several articles which are relevant to trafficking in human beings: „Enslavement and transportation of enslaved persons “ (article 418), „Trafficking in human beings“ (article 418-a), „Smuggling of migrants“ (article 418-6), „Organized group and incitement to commit the crimes of trafficking in human beings and smuggling of migrants“ (article 418-b), and „Trafficking in children“ (article 418-r).

<sup>101</sup> Compensation of victims of trafficking in the Republic of Macedonia - ESE, Open Gate 2014.

## (PSYCHOLOGICAL AND SEXUAL HARASSMENT AT THE WORK PLACE)

**The Law on protection against harassment at the work place<sup>102</sup> does not regulate behaviors which represent harassment at the work place neither define the harassment at the work place as a professional health risk** to the employees, which gives rise to the obligation to compose an assessment of the possible risks, as well as specific prevention measures against violence, and measures for building a healthy and safe work environment. Furthermore, the legal solution does not define and does not stress the aspect of victimizing the worker at the work place. Although, following the example of the European laws, the provisions in the Macedonian law do postulate preventive measures<sup>103</sup> aimed at protection against harassment at the work place, they are however declarative, imprecise, and incomplete, which leaves space for employers to do their own assessment when selecting the measures and methods for preventing such behaviour; thus, the Law meets only the form, but not the essence and goal of these measures.

The legislator has foreseen only a discretionary right for the employer to compose a list of mediators to be used to select one or more mediator that need to be a neutral person who will objectively and impartially mediate between the disputed parties. Such legal solution still brings the neutrality and objectivity of that person into question in the legally foreseen preliminary procedure (procedure in front of the employer) for protection against harassment at the work place. What should also be noted is the negative effect that the offered legal solution would create, which obliges the employer, if the wellbeing of the worker was harmed, to relocate him/her to another work area, until the procedure for protection against harassment is completed. This measure and the failure to provide an opportunity for employees to decide on their own regarding this measure, further contribute to their victimization.

Following the example of the Law on safety and protection at the work place and the foreseen essential role of the employee representative for safety and protection at work, the Law on protection against harassment at the work place needs to establish and regulate the function of an employee representative for protection against harassment at the work place. Additionally, the Law should regulate the special authority of this employee representative with regard to detecting and preventing acts constituting harassment at the work place, notifying the employer, taking measures to suppress such acts, but also an obligation on their part to notify and coordinate their actions with the State Labor Inspectorate. The Law on protection against harassment at the work place does not define the essential role of the State Labor Inspectorate, and hence its authority as an inspectorate should be increased by introducing quality mechanisms for regular and extraordinary supervision; in addition, the law should also introduce an obligation for issuance of measures of accountability of employers in case of harassment at the work place.

The court procedure for protection against harassment at the work place does not contain precisely determined deadlines for filing a lawsuit in cases when the employee receives a notification that the mediation was unsuccessful, or when the court has concluded that the has been stopped. Neither has the Law foreseen a deadline for filing a lawsuit from the day of the most recent act of harassment (statute of limitation) in order to prevent abuse by both parties, with such a deadline being possibly longer, since the worker needs time to realize that they are being harassed, to gather evidence, as well as courage to initiate a procedure.

**Criminal Code has still not incriminated the act of harassment as a separate crime, and hence the harassment victim is unable to seek criminal accountability from the person who committed the harassment.** Additionally, besides seeking accountability from the legal entity, the Law on protection against harassment at the work place should foresee personal accountability and punishment for the harassment perpetrator at the work place.

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<sup>102</sup> Official Gazette of RM no. 79/13 and 147/15).

<sup>103</sup> Art. 9 and Art. 10 of the Law on Protection against Harassment at the Work Place, consolidated text (Off. Gazette of RM no. 79/13 and 147/15).



Bearing in mind the fact the primary goal of the legislator is to prevent the acts of mobbing, i.e. their amicable settlement in an extrajudicial procedure, the Law on protection against harassment at the work place needs to address the possibility of using the provisions of the Law on amicable settlement of disputes.

### 3.3 ACCESS TO FREE LEGAL AID

**There is no specific legal provision that regulates legal aid for victims of violence.** Women victims as the other citizen in the Republic of Macedonia can apply for the right to free legal aid according to the Law on free legal aid<sup>104</sup>. Law on free legal aid guarantees equal access to justice by means of provision of free legal aid (in all instances of civil and administrative procedures and preparation for the legal documents) for persons who are financially disadvantaged and who fulfill the criteria/requirements laid down in the Law. One major obstacle for using this law by the gender based violence victims is that the administrative court taxes, costs for expert opinions, costs for obtaining evidence and other costs are not covered with the Law on free legal aid. In addition, as a result of the lengthy procedure for approval of free legal aid and the strict criteria for awarding it, the number of victims of violence who have exercised the free legal aid provided by the state is very small. In the absence of access to free legal aid, victims of violence take advantage of the existing services provided by civil organizations such as Association ESE<sup>105</sup>, Open Gate/La Strada or Coalition for sexual and health care rights of marginalized communities.

**Moreover, the funds allocated for free legal aid for vulnerable categories of population including victims of violence by the CSO's is much more higher, then the funds for legal aid allocated from the Ministry of justice.** As illustration, according to the data from the Association ESE's analysis: "The costs for legal aid for victims of domestic violence", the association within the Center for legal aid for victims of domestic violence provided following legal services: 570 pieces of legal advice, development of 220 written filings and court representation of six victims of domestic violence, with their value amounting to 739,980 MKD (11,950 EUR). On the other hand, the budget of the Ministry of Justice for provision of free legal aid is still insufficient and fails to ensure coverage of costs for free legal aid for all users and for all types of legal aid they need. For instance, the Ministry of justice spent only 414.909 MKD (6702 EUR) in 2014; 770.701 MKD (12.450 EUR) in 2015 and 740.910 (11.969 EUR) in 2016<sup>106</sup>.

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<sup>104</sup> Law on free legal aid, official Gazette of RM, no. 169/09.

<sup>105</sup> Since 2002, Association ESE's legal aid centre are providing free legal aid and representation of victims of domestic violence. Between 2002 to 2012 a total 2859 women sought help from the Center, with a total of 1282 filings, 106 criminal charges and 173 victims of violence represented free of charge.

<sup>106</sup> Annual report for the implementation of the Law on free legal aid, 2014, 2015 and 2016, available at:

<http://www.pravda.gov.mk/resursi.asp?lang=mak&id=06>

## **LIST OF RECOMMENDATIONS:**

### **1. RIGHT TO HEALTH (Article 12)**

#### **1.1 Maximum use of available resources**

- The State should establish budget policies which will guarantee that the health budget is: progressive, developing, non-discriminatory and provide equal access to the health services for the citizens, follow the general national economic policy and development;
- The State should ensure the programmatic and financial sustainability and continuity in the existing health policies and services and allocate more domestic resources for financing the health sector in the country and increase efficiency in the use of budget funds provided by foreign lenders and donors.
- The State should establish system which will improve the quality of health data and statistic, increase the possibility for providing updated and real time data as well as segregated data (eg. health statistic by ethnicity), which will be used as a base for further development of the health policies and structuring the strategies in the health sector;
- The State should ensure more savings in the health expenditures, through allocation of more funds for cheaper preventive services rather than expensive curative services. This will help the government to reduce the cost and shift the services from tertiary to secondary and primary level in the health system;
- The State should increase the level of proactive and reactive transparency in its financial operations, especially within the national level institutions, such as the Ministry of Finance, Ministry of Health, Health Insurance Fund, etc.;
- The State should adopt activities aimed for Roma communities in the preventive Programs of the Ministry of health, especially the programs concerning the improvement of the health and health care of women, mothers and children with proper budget allocation;
- The State should increase the planned coverage of women with the Program for cervical cancer screening and breast cancer screening with main emphasis on marginalized groups of women (Roma and rural women);
- The State should increase the amount of financial assistance for care at least to the amount of the lowest salary in order to reduce the burden from the unpaid care work of the household members, primarily women, who take care of adult person that is not able to take care of him/herself;
- The State should increase bed capacities for nursing and elderly care in public institutions and should lower the price for accommodation of the persons in these institutions;

#### **1.2 THE RIGHT TO HEALTH FROM A PERSPECTIVE OF VARIOUS VULNERABLE GROUPS**

##### **The health of the Roma people**

- The State should adopt Action plan for health of Roma and should allocate adequate budget funds for its implementation;
- The State should establish mobile medical units for outreach activities in marginalized communities (Roma and rural communities) with aim of identification and immunization of non-immunized children;
- The State should undertake urgent measures to provide primary gynecological health care in Shuto Orizari the largest Roma municipality in Macedonia, including but not limited to: subsidized specialization for gynecology for doctor(s) interested to work in the municipality, higher per capita payment and other relevant measures;
- The State should undertake all the necessary measures in order abolition of the practice of unlawfully charging for free of charge healthcare services in gynecological health care on primary level;
- The State should adopt and implement activities for comprehensive health education in Roma communities, with special emphasis on reproductive health, safe motherhood, child's health, immunization etc.;
- The State should allocate funds in order to cover expenses for co-payments of health care services in specialist-consultative care, hospital care and for purchasing prescribed medicines for people living in poverty and for beneficiaries of social assistance from the State;
- The State should undertake all the necessary measures in order to eliminate discriminatory practice against Roma people in terms of the enjoyment of the right to health on all levels of health care;

## **Women's health**

- The State should provide subsidies for specializations for the deficient medical specializations in order to meet the criteria prescribed in the Network of health care facilities on the entire territory of Republic of Macedonia, with priority to the medical specialists linked with women's health, including gynecologists, pathologists-cytologists, social medicine etc.;
- The State should employ sufficient number of patronage nurses in all of the municipalities in Macedonia in order to provide adequate services in the period of pregnancy and one year after the delivery, with special emphasis on Roma and rural communities;
- The State should adopt bylaw in order to define the scope of work of the patronage nurses, including number of visits, types of services that should be provided during each visit, special measures for vulnerable groups of population (Roma and rural communities) and coordination of the patronage nurses with different health institutions, including gynecologists on primary level and maternity hospitals;
- The State should prepare comprehensive analysis in order to assess the causes of the situation of high rates of perinatal mortality, infant mortality and maternal mortality and according to the findings should adopt adequate measures and allocate sufficient funds in order to address the identified problems and to improve the situation;
- The State should undertake measures in order to enable proper implementation of the Programs for screening of cervical cancer and breast cancer which will result in increased coverage of women with these services;
- The State should place the oral hormonal contraceptives on the List of medicines which expenses are covered by the Health Insurance Fund (positive list of medicines) in order to increase their usage and to reduce the use of abortion as a method of family planning;

## **Health of persons living with HIV/AIDS**

- The State should undertake measures for sensitization of the healthcare workers by including the topics of stigmatization and discrimination of persons living with HIV in the official curriculum and continuous training of healthcare workers;
- The State should establish effective protection mechanisms and to provide capacity building activities about HIV-related human rights needs to all relevant state agencies and institutions dealing with discrimination on grounds of HIV status;

## **Health of people who use drugs**

- The State should undertake measures for implementation of the recommendations given by the World Health Organization for the purposes of eliminating the existing obstacles to ensure better access to treatment of addiction;
- The State should assure unlimited realization of the right to choose a selected physician by persons who use drugs so that they can get a referral to relevant secondary and tertiary health care institutions and start a treatment from addiction to opiates (methadone therapy and buprenorphin therapy);

## **Health of persons with intellectual disability**

- The State should expand the realization of the right to health care and to allow exempt from co-payment for children/individuals with intellectual disabilities regardless of their age;
- The State should introduce measures to overcome the inappropriate treatment by health care professionals of persons with intellectual disability and shortcomings of the existing system in categorizing disabilities;
- The state should ensure exercising of the right to mobility of persons who do not use a "wheelchair";

## **Health of victims of trafficking in human beings**

- The State should introduce all necessary legal, institutional and financial measures to ensure the required health care of victims of human trafficking at all levels of health care;

## **Health of people with rare diseases**

- The Ministry of health should adopt legal measures to allow timely diagnose of rare diseases in or outside of R. Macedonia;
- The Ministry of health should develop a National plan for rare diseases with appropriate allocation of funds to ensure its implementation;
- The Ministry of Labor and Social Policy should adopt bylaws and introduce specific services for people with rare diseases separate from the services for persons with special needs;
- The Ministry of Health together with the Health Insurance Fund should determined precise criteria on the implementation of the Program for Rare Diseases including how are patients registered, which health institution and medical professionals are deciding on the treatment , when and for whom the treatment will be provided;
- The state should provide treatment and other necessities for the wellbeing of the patients with rare diseases (including but not limited to: orthopedic devices, special food, supplements, and etc.) since the fund in the Program for rare diseases are not sufficient to provide treatment for all registered patients with rare diseases;
- The Ministry of Health should have a patient representative in the Commission for Rare disease, to increase transparency and to work closer with patient organizations so that patients needs can be adequately met;

## **1.3 PROTECTION OF PATIENT RIGHTS**

- The State should undertake appropriate legal and all other measures in order to guarantee and ensure patients rights protection, especially measures for raising the level of awareness among patients and health care workers;
- The State should ensure establishment of the legally prescribed mechanisms for patients rights protection in order to ensure access to patients rights protection nation wide;
- The State should undertake measures in order to ensure timely, reliable and appropriate health rights protection, especially by the HIF and MOH;
- The State should undertake measures to ensure proper implementation of the Administrative court decisions in cases of health rights violations;

## **2. RIGHT TO GENDER EQUALITY AND LEGAL PROTECTION OF WOMEN VICTIMS OF VIOLENCE AND DISCRIMINATION (Article 3)**

### **2.1 MECHANISMS FOR PROTECTION AGAINST DISCRIMINATION AND UNEQUAL TREATMENT**

- The State should assure that the legally prescribed principle of shifting burden of proof to the potential discriminator is applied in practice by the Commission for protection against discrimination;
- The State should take measures and activities to provide efficiency and effectiveness of the mechanism for protection of the right to equal treatment of genders;

### **2.2 VIOLENCE AGAINST WOMEN**

#### **Sex work**

- The State should take measures for sanctioning all serious violations of human rights of women who provide sexual services, in particular violations made by the state institutions and ensure that sex workers have equal access to justice;
- The State should adopt measures to raise awareness on the health and safety risks of prostitution and eliminate barriers preventing access to health and social services for sex workers;

#### **Trafficking in women**

- The State should allocate financial resources regarding the realization of preventing the human trafficking, provision of necessary protection for victims of human trafficking and decreasing the prevalence of trafficking in juveniles;
- The State should adjust legal framework in order victim's need to be meet and right to compensation efficiently implemented;

### **Domestic violence**

- The State should assure efficient and proper implementation of the Law on domestic violence in practice, through creating basic preconditions : system of education of professionals, unified central data collection system for monitoring incidences and trends of domestic violence; organizational and human capacities development and management , that will assure effective and coordinative actions in domestic violence cases;
- The State should provide funds for implementation of the National strategy for domestic violence, which is exclusively dependant on foreign financial assistance as well as to ensure monitoring and evaluation of achieved results from its the implementation;
- The State should allocate sufficient financial support to NGO's that providing direct services for women victims of violence, including domestic violence;
- The State should take measures for affirmation of interim measures for protection from domestic violence, in particular on local level and take measures to assure issuing of restraining orders in the legally prescribed time limit;
- The State should adopt changes in the Criminal code in order to assure that all criminal acts on domestic violence are prosecuted by the state (ex officio), including criminal act bodily injury, which now is prosecuted upon the consent of the victim;

### **Psychological and sexual harassment at the work place**

- The State should review and supplement the legal provision on harassment at the workplace, to take measures for bigger affirmation and to introduce those measures for women, as well as to improve the treatment of this phenomenon;
- The State should adopt changes in the Criminal Code and incriminate the act of harassment as a separate crime;

### **Access to free legal aid**

- The State should provide effective access to free legal aid and legal representatives for the victims of gender-based violence, so that the latter may exercise their rights, including the right to compensation;

## ANNEX 1.

### **Case 1: Violation of the right to health of Roma women** (untimely performance of the surgical treatment)

Roma woman from Delcevo, on 16.05.2011 fell down the stairs and got fracture on the upper arm. Because of inadequate treatment, the condition of the client was worsened and the shoulder joint was significantly damaged. Namely, during the regular check up in the Public Health Institution Clinical Hospital in Shtip, it was found that the place in which the gypsum bandage was placed for the first time did not correspond to the state of injury and because of that client's health deteriorated. On 22.03.2012 client submitted lawsuit<sup>107</sup> to the Public Health Institution General hospital –Kochani and the doctor, so she has succeeded to finish civil court procedure with positive epilogue: Charging General Hospital to pay compensation in the amount of MKD 200.000 for physical and psychological damage for the suffering caused with the ill-treatment by the doctor. This procedure had a positive outcome.

In the meantime, patient's health condition significantly worsened and she needed surgery for placement of artificial shoulder joint. First hospital that she was referred to was the Public Health Institution General City Hospital "8 September" – Skopje in December 2011, where according to the medical documentation she was examined by the surgeon and the surgeon's opinion was that she needed to have a surgery for implantation of the artificial shoulder joint (endo-prothesis) in that hospital in the month of January 2012. The patient subsequently contacted the Hospital in the next period in order to schedule the needed surgery but it was constantly postponed without providing additional information to the client. Because of the delay of the surgery over a period of almost two years, the client was referred for the same treatment to the University Clinic for Surgical Diseases "St. Naum Ohridski" – Skopje in September 2013. The surgeon from this hospital confirmed the diagnosis and the need for the same surgical procedure (as in the previous hospital) and stated in the document that this procedure would be performed on the client in "St. Naum Ohridski" Hospital. The surgeon referred the client for pre-operational examinations and preparation. Despite the fact that the patient had the needed pre-operational examinations, the surgical procedure was not scheduled in the subsequent months, without any reason given for the delay.

Taking into consideration the situation and the delay in the performance of the surgical treatment for 2 (two) years, in November 2013, on the behalf of the client we sent a written submission to the State Sanitary and Health Inspectorate (SSHI) for the violation of patients' rights i.e. right to timely medical treatment and right to obtain timely and adequate information (including information of the reasons for delaying the necessary surgical treatment, i.e. placement of an artificial shoulder joint) in order to conduct inspection supervision. At the end of December, 2013 the SSHI informed us that this type of surgical procedure (implantation of artificial shoulder joint) is not performed in the public health institutions in Macedonia and that the patient should submit a claim to the Health Insurance Fund for having the medical treatment abroad. To have precise information where this kind of surgical treatment is performed, association ESE sent Requests for free access to public information. From the provided replies, contrary to the answer of the SSHI, it was stated that the needed medical treatment is routinely performed in the hospitals where the patient was referred.

In February 2014, a Request for urgent intervention to the Ministry of Health (for untimely treatment) was submitted. The Ministry of Health replied by letter dated 26.02.2014, that the Ministry does not have a mandate to decide upon this issue and that they referred the request to the Medical Chamber of Macedonia for further proceeding. Since there was huge delay and no reply from the Medical Chamber, in July and November 2014 a letter for urgent intervention to the Ministry of Health was send. The Ministry did not respond till the submission of the court lawsuit.

As a result of untimely and inadequate treatment and failure to provide access to information crucial for the client's health status, and since the needed operation has not been performed to date, the client's condition has gotten worse. The last opinion provided by the specialist in January 2015 indicates that the movements of the right shoulder were completely stiff.

In June 2015, association ESE requested additional medical documentation needed for the process of initiating lawsuit (dated 02.10.2015) to the Ministry of health for violation of the right to health. The finding and the opinion of the expert witness (general surgery specialist and trauma subspecialist) states that the patient has suffered from severe bodily injury which entails sublaxation (partial dislocation) of the right shoulder, or partial dislocation of the bone, which necessitates

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<sup>107</sup> Court procedure for damage compensation was supported by the CSO's Roma SOS, Prilep



that the joint be fixed and restored to the original position within a brief period of 2-3 weeks following the injury, but after that, only a surgical intervention can heal the injury, which despite of the examinations has to date not been done. Hence it ensues that due to the delay in the surgical intervention, the patient is exposed to incessant pain and suffering and permanent disability on her right shoulder. After the submission of the lawsuit, two hearing was held, second on 25.04.2016. Ministry of health did not request for additional medical expert opinion. It is expected decision to be brought this June. If the court brought positive decision and determined violation of the patient rights, the next step will be submitting a lawsuit for ill-treatment and request for damage compensation.

The Letter of complaint elaborating the above mentioned cases was send by the Association ESE to the Special Rapporteur on the right to health on 25.01.2016, where we request the Special Rapporteur to call the R. of Macedonia and the Ministry of health for urgent action, i.e. providing immediate medical treatment.

**Case 2: Violation of the right to health of Macedonian men (refusal for providing medical treatment with the new NUSS method)**

The client who suffering from “pectus excavatum/pectus infundibiliforme” was surgically treated for his condition in 1995 using the Ravitch method, but his health condition is constantly worsening and now he has a need to undertake another surgical procedure according to NUSS method (since it has been proven that the Ravitch method cannot improve his condition). His deformity is in advanced stage and is accompanied by impairment of lung function, restriction of lung capacity and initial compression on the heart muscle.

In 2009, the client went to the Private Hospital “Filip II” to conduct analysis on his deformity and to make consultations for the possibilities for improvement of his health condition. By the medical team in the Hospital it was concluded that it is vitally needed the surgical treatment using NUSS method to be performed. Medical certification and opinion was provided in order patient to address the Health Insurance Fund (HIF) for covering the necessary costs of the required operative treatment. Later on that year, he was accepted by the Clinic for Thoracic and Vascular Surgery for 5 days, and later discharged from the hospital with the explanation “Due to technical reasons, surgery is delayed for 2-3 weeks. You will be additionally invited for admission”. He was not invited again.

In the beginning of 2012 client submitted Request for referral for treatment abroad to the Health Insurance Fund- HIF (since in Macedonia the surgery according to NUSS method is not performed) and he was rejected with explanation that he didn't exhausted all possibilities for treatment domestically, and that there is possibility to conduct the surgery with application of the older method i.e. Ravitch method (method that was proved to be inefficient for the patient).

In December 2012, patient submitted second Request for referral for treatment abroad or in some of the private clinics in the country. In January 2013 he was rejected again by the HIF and at the same time he was referred to the Clinic for Thoracic and Vascular Surgery to take a medical intervention on Ravitch method. In February 2013, the client sent an appeal to the Management Board of the Health Insurance Fund which was rejected as unfounded. Based on the last decision of the HIF, in March 2013, association ESE prepared and initiated lawsuit in front of the Administrative Court, requesting that this HIF decision should be annulled and the case should be reexamined/reconsidered by the HIF. Since there was no reply from the Administrative Court, three urgent interventions was prepared and submitted in October 2013, March 2014 and June 2014 in order to accelerate the court procedure.

In August 2014, Administrative Court brought decision according to which lawsuit is granted, the contested HIF decision is annulled and the case shall be returned for re-examination at the first instance (in front of the HIF). After the decision of the Administrative Court was brought, at the beginning of September, 2014, HIF requested from the University Clinic for thoracic and vascular surgery in Skopje to provide expert opinion on the health status and the needed treatment for the client by the medical consilium. On 25.12.2014 again the client received decision from the Health Insurance Fund with which the request for treatment abroad was rejected. Thus, on 08.01.2015 an appeal was prepared and submitted to the Management Board of Health Insurance Fund-HIF, which rejected the request for treatment abroad for the second time. In February 2015 lawsuit has been prepared and submitted to the Administrative Court again. It should be stressed that Administrative court is not efficient remedy, since the fact that there is negative practice by the court to not decide with merit decision, but rather to abolish the appealed act and to return the procedure for decision in the first instance

institution. Thus, in September 2015, again Administrative Court brought decision according to which the contested HIF decision is annulled and the case shall be returned for re-examination at the first instance (in front of the HIF).

After seven years of requesting proper implementation of the right to highest attainable standard of health, in January 2016, management board of the Health insurance Fund granted the client with the right to medical intervention according to the new method in the private hospital.