

REPUBLIC OF MACEDONIA

Joint Submission

For Consideration by the Committee on Economic, Social and Cultural Rights at its 56th Session

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Joint Submission from Association for Emancipation, Solidarity and Equality of Women-ESE

With:

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

Roma Organization for Multicultural Affirmation - ROMA SOS Prilep

Open Gate – La strada

The association of citizens for rare disease “Life With Challenges”

Center for Democratic Development and Initiative -CDRIM

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1. INTRODUCTION

The Association for emancipation, solidarity and equality of women– ESE¹, 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) 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 the Open Society Foundation, New York and Macedonia, we put together this submission to highlight the problems associated with non-fulfillment of the **Right to health** (article 12 of the International Treaty on Economic, Social and Cultural Rights 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 in this submission from the perspective of the application of article 2.1 of the Treaty- Maximum Use of available resources. The Submission aims at contributing to the consideration and formulation of the List of issues at the Committee’s Pre-Sessional Working group in October, and to raise questions to the Government of RM for the fulfillment the right to health as regulated in the Covenant.

2. MAXIMUM USE OF AVAILABLE RESOURCES (Article 2.1.)

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%, compared to the unspent funds in curative care which on average stand at 2% annually.

Guided by the recommendation given by the Special Rapporteur on the right to health² 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 individuals, such as Roma people, women and children. Therefore the budget for the Programme 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 environments with a special focus on the Roma people. As a result, Roma families receive 1.5 visits by the patronage nurses instead of 9 visits³. Also, the activities from the Programme which pertain to antenatal checks and microbiologica smear tests of pregnant Roma women who are recipients of social assistance, unemployed or from family receiving minimum income were not realized because of absence of implementation mechanisms, and were thus removed from the implementation plan⁴.

The Programme for early detection of carcinoma of uterus which envisages coverage of 20% of the women who have been defined as a target adult group covers only 10 – 15%. The Breast cancer screening programme has not been implemented for four years (2011-2015), although it is approved and budgeted every year.

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 People⁵. At the same

¹ 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.

² 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.

³ 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.

⁴ “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>.

⁵ 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.

time, the state has no reports or data available at an annual or any other level on the basis of which it could monitor and evaluate the progress of the Decade of Roma and National Action Plans for Health care⁶.

Notable is the trend of non-transparency and absence of accountability of the Ministry of health and public health care institutions concerning health care and public health care institutions as regards their financial operations. For example, in 2014 the Ministry of Health showed a decline in the level of pro-active disclosure of information and a drop in the level of reactive transparency (from party reactively transparent in 2013 it turned into reactive non-transparent institution)⁷.

This situation refers to the data on foreign aid. 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 in the amount of EUR 7 428 800. 00 intended for improvement of health care of mothers and children in the Republic of Macedonia⁸, 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 budget⁹.

3. THE RIGHT TO HEALTH FROM A PERSPECTIVE OF VARIOUS VULNERABLE GROUPS (Article 12 and General Comment no.14) (THE HEALTH OF THE ROMA PEOPLE)

Unfavourable 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 MKD¹⁰.

Roma are not adequately covered with specific measures of preventive health care measures intended for Roma communities and provided in the Programmes of the Ministry of Health¹¹. Namely, Roma women in the municipality of Shuto Orizari¹² during pregnancy and after birth of a child are visited on average 1,5 times by a patronage nurse instead of the mandatory nine visits¹³. 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, Vinica, Gorche Petrov, Saray and Karposh¹⁴. 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%¹⁵.

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 examination¹⁶. 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.¹⁷

⁶ 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>.

⁷ Available in Macedonian: <http://esem.org.mk/en/pdf/Publikacii/2015/ESE%20transparency.pdf>;
<http://esem.org.mk/en/pdf/Publikacii/2014/Najzavoreni%20institucii%20za%20javnost%20za%202013.pdf>;
<http://esem.org.mk/en/pdf/Publikacii/2014/Najnetransparentna%20institucija%20vo%20RM%20za%202013.pdf>;
<http://esem.org.mk/en/pdf/Publikacii/2014/Proaktivno%20netransparentni%20za%202013.pdf>.

⁸ What is happening with the money from the Dutch grant ORIO OPIIO 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/Publikacii/2014/ESE%20Grant%20ORIO.pdf>.

⁹ 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/Publikacii/2014/ESE%20Grant%20ORIO.pdf>.

¹⁰ 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>.

¹¹ The programme for active health care of mothers and children and the Programme for general health checks of pupils and students.

¹² 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

¹³ 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 Programme for active health care of mothers and children. Association ESE and CDRIM. 2014.

¹⁴ 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%20orabotime/2014/1/Opfat%20na%20decata%20Romi%20so%20vakcinacija.pdf>.

¹⁵ Ibid.

¹⁶ Knowledge gained from field work by the Center for democratic development and initiatives – CDRIM and Roma Resource Center – RRC.

¹⁷ 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>.

Roma women are not to a sufficient extent covered with the Programme for carcinoma of uterus screening, namely only 19% of Roma women at the age of 24 – 60 have been covered with gynecologist examination with PAP test under the Programme in the period 2012 – 2014¹⁸. 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 gynecologist¹⁹. Also, experience from the ground shows that in Shuto Orizari there 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 personnel²⁰.

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 form Roma is the physical accessibility of such services. Namely, the Polyclinic in the municipality of Shuto Orizari²¹, 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 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 patients²². 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 for 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 seriously²³. 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 files²⁴. Failure to provide quality health care services leads to serious injuries and 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.²⁵ At all levels of health care there are cases of disrespect of cultural and traditional practices of Roma shown by health care professionals²⁶.

According to the research²⁷ 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 live²⁸. 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.²⁹ 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 care³⁰.

¹⁸ Research carried out in the municipality of Shuto Orizari, Delchevo, Pehchevo and Vinica as part of the work in the field of monitoring in the community for the coverage of Roma women with carcinoma of uterus screening programme, Association ESE, CDRIM and KHAM, 2015.

¹⁹ 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>.

²⁰ Knowledge gained from filed work by the Roma Resource Center (RRC) and the Center for Democratic Development and initiatives (CDRIM)

²¹ According to official data, majority of Roma live in Skopje (23.475), of whom 56% are concentrated in the municipality of Shuto Orizari.

²² 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>.

²³ Petition filed for determination of violation of the right to health against the Ministry of Health. September 2015 (Association ESE and KHAM).

²⁴ Knowledge gained from filed work of NGO KHAM.

²⁵ 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.

²⁶ 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.

²⁷ 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>.

²⁸ Knowledge gained from the field work by Roma Resource Center (RRC).

²⁹ Knowledge gained from the field work by the Center for democratic development and initiatives- CDRIM.

³⁰ 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 complaint³¹.

The unfavourable financial status of Roma people 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 pocket³².

(WOMEN'S HEALTH)

Women in RM are insufficiently covered with health care services including primary gynecological health care, and some of them are not happy with the health care services in maternity wards. The main reason for this is the insufficient number of selected gynecologists and their uneven territorial distribution. In 2014 in RM there were only 138 gynecologists,³³. 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 insufficient³⁴. As a result only 45,6% of women at the age of 14+ have a selected gynecologist³⁵. According to ESE, in terms of antenatal care, 17% of women had less than four checks³⁶ during the first pregnancy, while 2% never had any checks at all³⁷.

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 ESE³⁸, 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 ESE³⁹, 15% of women in their reproductive period have had a minimum of one abortion in their life, or on average every woman has had two abortions. The most frequently mentioned reason 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 PEOPLE LIVING WITH HIV)

People who live with HIV cannot exercise their right to health equally and without being discriminated. According to the research on the needs of people living with HIV⁴⁰, one quarter of them have reported that they have been refused health care services. Equal number of people have 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 discrimination.

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 favour⁴¹. 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 issued⁴², 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

³¹ 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).

³² Ibid.

³³ Health Insurance Fund of R. Macedonia, Annual report for 2014

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

³⁴ 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.

³⁵ Analysis of Association ESE based on „Annual report for 2014“ of the Health Insurance Fund of R. Macedonia.

³⁶ According to WHO recommendations for pregnancy checks are prescribed.

³⁷ 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>.

³⁸ Ibid.

³⁹ Ibid.

⁴⁰ http://hera.org.mk/wp-content/uploads/2015/02/Istrazuvanje_HIV-2014.pdf.

⁴¹ http://hera.org.mk/wp-content/uploads/2015/02/Istrazuvanje_HIV-2014.pdf.

⁴² Opinion of the Commission for protection against discrimination AS vs PHI Anchevski Laser Lab no. 07-483/6 од 27.03.2013.

health inspectorate found when proceeding on a complaint that it was not a case of discrimination⁴³, while the Ombudsman found that there was discrimination on the basis of a health status (HIV)⁴⁴.

(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 minorities⁴⁵.

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 level⁴⁶.

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.⁴⁷

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 Gate⁴⁸ 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 coverage⁴⁹, still they face problems in the exercising of their rights to health because they are placed in the shelter in Skopje, and their family

⁴³ Correspondence from the State sanitary and health inspectorate no. 16-2100/4 dated 09.12.2014.

⁴⁴ Opinion of Ombudsman no. 3512/14 dated 12.12.2014.

⁴⁵ HOPS 2011, Improving access to social and health care for Roma who use drugs. Skopje: Healthy Options Project Skopje.

⁴⁶ 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.

⁴⁷ Report from the survey carried out by RCPLIP- PORAKA, available at www.poraka.org.mk.

⁴⁸ <http://www.lastrada.org.mk/userfiles//Analiza%20Otvorena%20Porta%20%28finalna%2025%2009%202012%2013%281%29.pdf>.

⁴⁹ 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“.

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)

Diagnosing of rare diseases is a problem faced by families in R. Macedonia (most often because of a lack of re-agents, technology and the like). Then again, the state does not cover the costs of diagnosing such conditions abroad. There is no standardized approach to the treatment of those suffering from rare diseases in Macedonia, as there is no adequate classification and registration of rare diseases at a national level. 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 Programme 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 taxes⁵⁰, it is expected that procurement of drugs will be made possible for an increasing number of rare diseases.

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.

4. LIST OF QUESTIONS:

Maximum use of available resources

- What are the reasons for the state to allocate more funds to curative as opposed the preventive health care?
- What are the reasons for the funds for preventive health care to decline continuously during a fiscal year and what are those funds diverted to?
- What is the reason for the state to plan with the Programme for detection of carcinoma on uterus coverage of only 20% of women defined as adult target group with activities for organized screening with the screening in reality covering only 10 – 15% of the target group of women? What does the state do to increase the coverage of women with organized screening of carcinoma of the uterus?
- What are the reasons for the state to reduce the budget for the Programme of health care for mothers and children every year (a programme which provides the key measures for promotion of the health of mothers and children), which is highly pronounced through frequent changes in the budget of the programme in one fiscal year?
- Why has the state during the period between 2006 to 2011 failed to allocate sufficient funds for the activities specified in the National action plan for the health of the Roma people. How much money has the state spent over the same period for the implementation of the activities of the National action plan for the health of the Roma people?
- What are the measures the state has undertaken for enhancement of transparency and accountability of state institutions and public health care institutions in terms of their financial operations including the grant ORIO provided by the Kingdom of Netherlands?

The health of the Roma people

- Why doesn't the state maintain health care records / statistics by ethnicity in particular because specific measures are provided intended for promotion of the health of specific groups including Roma?
- Why doesn't the state allocate funds from the budget for preventive care intended for Roma such as additional visits by patronage nurses under the Programme for health care of mothers and children?
- How much money the state has spent from the Programme for health care of mothers and children for the realization of activities in Roma communities in the period 2011 to 2014, broken down by year?
- What are the measures taken by the state to enable full access of Roma women to primary gynecological care (provision of gynecological health care in the municipality of Shuto Orizari, abolition of the practice of unlawfully charging for free of charge healthcare services and elimination of discriminatory practice in terms of the enjoyment of the right to a selected gynecologist)?
- What are the measures undertaken by the state to overcome the physical and economic availability of services of specialist-consultative care and hospital care?
- What are the measures undertaken by the state to eliminate discriminatory practices against Roma people at all levels of health care?
- What are the measures taken by the state to allow full realization of the right of access to medicines?

Women's health

⁵⁰ Under the Law on Excise taxes one Macedonian denar from each packet of cigarettes shall go to the Rare Diseases Programme.

- What are the measures undertaken by the state to provide even coverage of women with gynecological health care in conditions of insufficient number of gynecologists in primary health care and uneven territorial distribution of primary care gynecologists by region??
- Is the state planning to introduce specific systemic measures for increased coverage of women from marginalized groups (Roma women, women from rural communities etc) with activities provided in the Carcinoma of uterus screening programme and Breast cancer screening programme?
- What are the systemic measures which are undertaken by the state to increase the level of utilization of modern means of contraception in order to reduce the use of abortion as a method of family planning?

Health of people living with HIV/AIDS

- What are the measures undertaken by the state to ensure availability and access to health care services which are free from stigma and discrimination of people living with HIV?
- What are the measures undertaken by the state to sensitize health care professionals and employees in institutions and bodies for protection against discrimination with a view to provide information on the latest achievements regarding efficient prevention and treatment of HIV?
- What are the measures undertaken by the state to improve the proceedings regarding the mechanisms of protection of the rights of people with HIV status?

Health of people who use drugs

- What are the measures undertaken by the state to implement the recommendations given by the World Health Organization for the purposes of eliminating the existing obstacles to ensure better access to treatment of addiction?
- How will the state provide 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

- Why does the government exempt from co-payment for realization of the right to health care only children/individuals with intellectual disabilities of up to 26 years of age and what measure will it take to expand the realization of this right by all the others regardless of their age.
- What are the measures undertaken by the state to overcome the inappropriate treatment by health care professionals of persons with intellectual disability?
- What are the measures undertaken by the state aimed at overcoming the shortcomings of the existing system in categorizing disabilities?
- What are the measures undertaken by the state to ensure the exercise of the right to mobility of persons who do not use a “wheelchair “?

Health of victims of trafficking in human beings

- What are the measure undertaken by the state to ensure the required health care of victims of human trafficking at all levels of health care?

Health of people with rare diseases

- Is the Ministry of health planning to pass legal measures to allow timely diagnose of rare diseases in or outside of R. Macedonia?
- Is the Ministry of health planning to develop a national strategy for rare diseases in Macedonia with appropriate allocation of funds to ensure its implementation?
- What are the measures undertaken by the state for the purposes of additional funding of the Programme for rare diseases to ensure higher coverage and improved health and social care services?