Public Policy Document

ACCESS TO PRIMARY HEALTH CARE FOR ROMA WOMEN AND WOMEN WITH DISABILITIES DURING AND AFTER COVID-19

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ЗДРУЖЕНИЕ ИНИЦИЈАТИВА ЗА ПРАВАТА НА ЖЕНИТЕ ОД ШУТО ОРИЗАРИ

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ИНКЛУЗИВА

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In the course of 2023, in cooperation with the civil society organisations "Polio Plus" – Movement against Disability, Association for Promotion and Development of Inclusive Society – "Inkluziva" and the Šuto Orizari Women's Initiative, HERA conducted research entitled "Access to Primary Health Care for Roma Women and Women with Disabilities During and After COVID-19". This research contributed to a better understanding of the level of impact the different factors have had on the access to health services at the primary level of the healthcare system, particularly to preventive health services, for two vulnerable population groups – Roma women and women with disabilities. The research particularly addressed the impact of the COVID pandemic, as a healthcare emergency, but it also described the feeling of being discriminated against when provided with health services by general practitioners, the presence of corruption when trying to obtain certain health rights, the cultural and personal factors related to prevention and vaccination etc. This study is expected to be further used to influence the policy makers and other stakeholders from the healthcare sector and wider, to improve the availability and accessibility of the primary healthcare system for these two vulnerable groups of women, and to help prepare for possible future cases of emergency.

The results were received through a survey conducted among the Roma women and women with disabilities, and some of the findings were further verified and examined in depth in interviews with women that play an active role in improving the social conditions for the two target groups.

The research found that certain improvements have been made in the realisation of health rights, particularly for Roma women, but it also established the fact that weaknesses and great challenges still exist in certain areas. The problem with acquiring the right to health insurance remains unresolved for people without identity documents, who mainly come from the Roma ethnic community. The awareness about the need for preventive examinations in the two target groups is at a relatively low level, and was particularly pronounced during the COVID crisis. There exist serious systemic shortcomings in the system that is supposed to stimulate and encourage the women to take regular preventive examinations related to their general, but also to their reproductive health. The attitudes of these two target groups regarding the regular vaccination of children are exceptionally positive, whereas vaccination against the Coronavirus was accepted somewhat reservedly.

The treatment by general practitioners, the physical accessibility of their medical offices, and the availability and understandability of information was scored exceptionally high by the Roma women, although individual cases of discrimination have also been registered. Roma women also gave high scores to the health facilities where they were provided with COVID-

related health care. Unlike them, women with disabilities are still facing great challenges mostly related to the accessibility of the medical offices and other health facilities, and to the understandability and availability of information in proper format in all segments of realising their health rights.

This research also revealed certain experiences with “petty” corruption related to acquiring the right to health insurance, and it verified the still present unlawful charging of women by their general gynaecologists for the health services they provide.

A large corpus of measures to be implemented in the future includes measures that should target the system as a whole, such as encouraging and structuring the general practitioners’ preventive activities; measures to combat the unlawful charging of health insurance holders in the process of registering for their health insurance, and when provided with health care by their general gynaecologists; awareness raising and health education; revision of payment policies regarding medicines; and exemption from co-payment for women at special socio-economic risk and for services provided during the process of acquiring the disability-based entitlements. The research indicates that these systemic activities will also affect, to a great extent, the vulnerable categories of women. Moreover, it is necessary to improve the standards on physical accessibility of the general practitioners’ medical offices in general, as well as the availability of information in a language that is easy to understand on all levels of the healthcare system, and which will be adapted, among other things, to the needs and abilities of people with certain types of disabilities. These measures would have a significant impact on the realisation of health rights for the Roma women and women with disabilities.

01 HOW THINGS STOOD?

Regulations and Principles

Law on Health Protection

Article 9 – "The principle of equity shall be accomplished by prohibiting discrimination when providing health care on grounds of race, sex, age, nationality, **social origin**, religion, political or other conviction, property status, culture, language, type of disease, **psychical or bodily disability**."

Law on the Protection of Patients' Rights

Article 5 – "The patient shall have the right to realise the rights laid down in the present Law without discrimination on grounds of race, colour of skin, origin, **nationality or ethnicity**, sex, gender, sexual orientation, gender identity, **belonging to a marginalised group**, language, citizenship, **social origin**, **education**, religion or religious belief, political conviction, other conviction, **disability**, age, family or marital status, property status, health status, personal characteristics or social status or on any other ground."

Article 8 – "The **information** that, under the present Law, the patient has the right to receive in all stages of health care must be provided in an **understandable and appropriate manner** for the patient, by minimising the technical, that is, specialised terminology, and for people with disabilities, adapted to the needs and abilities of the patient, in order to obtain the information which is relevant for the treatment of the patient."

Article 11 – "The right to information shall also be granted to the patient with permanently **diminished capacity of judgement**, in corespondence to his physical, mental and psychical condition, as well as to his guardian or legal representative."

Law on Health Insurance

Article 34 – "From **co-payment** (for health services and medicines) shall be **exempted:** … - children with disabilities, according to the regulation on protection of children (child protection), - beneficiaries of the guaranteed minimum aid, which are people incapable of work and beneficiaries of alternative care, according to the regulation on social protection, except for the medicines from the list of prescription medicines in the primary healthcare system and for treatment abroad, - mentally ill people placed in psychiatric hospitals and people with intellectual disability without parental care…"

Law on the Prevention and Protection from Discrimination

Article 4 – "**Adequate adaptation shall** be necessary and adequate modification and adaptation shall be needed in certain cases, which do not cause disproportionate or unnecessary burden, with the purpose of ensuring the enjoyment or realisation of all human rights and freedoms to people with disabilities, on an equal footing with everyone else. Preventing the adequate adaptation shall be considered discrimination. … Preventing the availability and accessibility of information, goods and services shall be considered discrimination."

COVID in Macedonia and the Impact on Vulnerable Populations

~19.000

cases of COVID-19 / 100,000 residents

~ 47,5 %

of the population has been vaccinated

Limiting factors for accessing the health care

- The examinations and consultations performed in the medical offices reduced.
- The intensity and the manner of operation of the medical offices changed, and some were transformed into COVID centres.
- The fear from contracting the Coronavirus in patients, but also in the doctors from the primary healthcare system, was enormous.
- Some of the patients were unable to reach the health facility due to disruptions in the public transport, and in the period of quarantine, which particularly affected the people with disabilities.
- Some patients postponed their requests for medical care, and others did not show up in medical offices at all, due to the recommendations to self-treat the ailments presenting with lighter symptoms.
- Threat to mental health was also identified, particularly in people with disabilities; UNICEF and the University Clinic of Psychiatry introduced telephone lines for psychosocial support, however, the information provided by telephone were not available to all people with different types of disabilities.

Positive practices for maintaining the health services

- Hospital treatment of COVID patients was completely free of charge, regardless of their insurance status.
- Electronic prescription was introduced for chronic conditions, so as to reduce the contact between the patients and the health service providers.
- Telephone consultations and a video-conferencing pilot project were introduced in the “My Appointment” electronic healthcare system.

- An online platform was developed for registration of those interested in getting COVID-19 vaccines.
- The administrative procedures falling under the competence of the Health Insurance Fund (the Fund) were temporarily relaxed by using electronic communication; for example, the realisation of the right to sick leave for employed people.

The Primary Healthcare System

Primary health care in Macedonia is provided by health centres, as part of the public sector, and by the general practitioners' medical offices, which are private facilities, but operate within the system of the mandatory health insurance. This set-up ensures universal health coverage.

Public health facilities (health centres)

Preventive health care – immunisation (vaccination), preventive dentistry, comprehensive medical evaluation

Access at home and in emergencies – community nursing service, emergency service (first aid), home-based treatment, out-of-hours service, rural teams

Private health facilities (medical offices of the chosen / general practitioners in teams with nurses)

General medicine – general practitioners, family medicine specialists, paediatricians **~ 1,500 total**

Gynaecology – gynaecology and obstetrics specialists **~ 150**

Dentistry – dentistry specialists **~ 1,200**

The teams of the chosen primary care providers:

- take care of the health of people that hold health insurance with the Fund and who have chosen them as their general practitioners,
- provide health care in cases of disease, injury, acute need, chronic condition,
- provide preventive health care, that is, they deliver services related to prevention and early detection of certain health conditions and illnesses (stimulated by state measures).

Population's health indicators show that the primary healthcare system is faced with many challenges:

- availability of human resources, particularly family medicine specialists and gynaecologists,
- their distribution and accessibility,
- awareness of the population about prevention, people's engagement, health education etc.

Perceptions of Corruption in the Healthcare Sector

Corruption in the healthcare sector is **insufficiently treated** in the relevant reports on corruption, but in many surveys the people have expressed their perception of the high level of corruption in the healthcare sector. The Ministry of Health **makes no risk assessments regarding corruption**, and it is not mentioned in any of the strategic documents for this sector.

The public health system is complex and comprises different elements – public institutions responsible for issues in the area of health care, public and private health facilities, and pharmaceutical wholesalers. For this reason, it is not possible to make a general statement as to the general existence of corruption in every segment of the healthcare sector. Also, the types of corruptive practices may vary.

The level of corruption at the primary level of health care and the people's experiences have not been assessed systematically before. The segment where an unlawful practice was found to exist beyond any doubt, which directly impacts the level of payment by individuals, is the unlawful charging for health services by general gynaecologists, which affects the access to primary gynaecological care. This situation has been documented over an extended period of time, and has been documents by the civil society sector, but the country has not yet established an efficient mechanism to deal with this systemic problem.

02 WHAT WE FOUND OUT?

The research contributed to clarifying the following questions:

- What social, economic, organisational, cultural and personal factors affected the access to primary health care for Roma women and women with disabilities during the health crisis caused by COVID (2020 and 2021), particularly focusing on the preventive health care?
- What is the awareness of Roma women and women with disabilities about the significance of preventive health examinations?
- What types of preventive health services were demanded in times of the crisis caused by COVID and how available were they?
- What are the experiences of our respondents related to COVID testing and treatment, and what are their status, attitudes and experiences with vaccination against COVID-19?
- What is the difference in access to health services in the primary healthcare system in this period compared to the period of crisis caused by COVID?
- What are the experiences of the respondents during the visits to and contacts with the medical offices of their general practitioners regarding accessibility of the medical office and the level of discrimination?
- What are these target groups' perceptions and experiences with corruption in the healthcare sector, particularly in the primary health care?
- What are the target groups' attitudes as to how the access to the primary health care could be improved following the end of the COVID crisis, and what lessons can be learned for future emergencies?

Some 260 women, members of the target groups – Roma women and women with disabilities – from several towns in Macedonia expressed their views on these questions.

The research found that certain improvements have been made in the realisation of health rights, particularly for the Roma women, but it also established the fact that weaknesses and great challenges still exist in certain areas.

Area Identified	Positive results	Area Identified weaknesses and challenges	
		Women with disabilities	Roma women
Health insurance and chosen primary care providers	* The percentage of **health insurance coverage is high**, particularly for children * The rate of women who have chosen a **general practitioner** and a **general dentist**, as well a general practitioner for their children, is high * The rate of women who have chosen a **general gynaecologist** is similar, with some indications even that it is **higher than that of the general population**	* **The level of information is low** about the ways in which one can verify one's health insurance status and the status of the chosen primary care provider in all three medical professions, and the format and the language in which this information is provided is not adapted to the needs and abilities of the people who are deaf or hard of hearing, blind or partially sighted, but also who have intellectual disability * Cases have been recorded of the unlawful practice of **charging a certain amount of money** for registering the women with disabilities in the health insurance system, that is, for filling out the required documentation by intermediaries * **Some 30% of women with disabilities have not chosen a general gynaecologist yet,** many because they are not aware of the need to do so, but also because they have no information where to do this	* **People with no identity documents** (some 5% of the population targeted with this research) are still remaining outside the health insurance system * **The level of information is low** about how one can check one's health insurance status and the status of the chosen primary care provider in all three medical professions * Cases have been recorded of the unlawful practice of **charging a certain amount of money** for registering the Roma women in the health insurance system, that is, for filling out the required documentation by an intermediary, either an employee of the Fund or a random person prowling the entrance of the Fund's premises * **Some 30% of Roma women have not chosen a general gynaecologist yet**, many because they are not aware of the need to do so
(Preventive) Health services	* Reminding the Roma women and women with disabilities that thy ought to undergo certain preventive examinations is giving results, and almost all the women who have received **invitations** from general practitioners have shown up for an appointment * Half of the survey participants have had a **Pap test** in the past 3-4 years, which does not differ from the coverage ratio of the country as a whole: the pillar of this preventive activity for the Roma women and women with disabilities are the general gynaecologists * Roma women and women with disabilities have **a positive attitude** about vaccination of their children, and only one of the survey participants said she had not taken her children to vaccinations	* **Some 23% of the respondents have examinations more seldom than once every two years** and as needed, implying that most likely they never go for regular preventive examinations * As many as 30% of the respondents from the above 24 age category have never done an **ECG**, which is even more pronounced in people with intellectual disability and people with combined disability * 63% of women with disabilities above 35 years of age have never received an **invitation by mail** from their general practitioners to go for a preventive examination * 22% of women with disabilities have never done a **Pap test**, most of whom hold the opinion that there is no need to get the Pap test if "nothing hurts them"; accessibility of the medical office was given as a reason by 4.5%, and as many wom-	* **38.5% have never contacted their general practitioner by telephone**, which is significant because telephone contacts became exceptionally important during the **COVID** crisis * As many as 25% of the respondents above 50 years of age and 42% of the Roma women aged 25-49 have said they have never done an **ECG** * 85% of the Roma women above 35 years of age have never received an **invitation by mail** from their general practitioners to go for a preventive examination * Half of the Roma woman do not get regular Pap tests, majority because they do not have a general gynaecologist, and one-quarter because "nothing hurts them"; 20% of the Roma woman have never had **a Pap test**

Area Identified	Positive results	Area Identified weaknesses and challenges	
		Women with disabilities	Roma women
(Preventive) Health services		en with disabilities specified that the reason was unadjusted equipment; distance to the gynaecologist's office was not identified as a reason, nor was the COVID crisis * Only 30% said they were regularly having preventive dental examinations, but for 2/3 of them this practice was affected by the COVID crisis, so they failed to do any examinations in this period. 60-65% do not go for preventive examinations with their dentists, majority because "they have no issues", and some of them because "they have not chosen a general dentist". It was not possible to establish the effects of the type of disability on the respondents' attitudes * The identified issue with **charging** the women for examinations performed by their **general gynaecologist** still remains	* 72% of the Roma woman do not see a dentist without having an issue; the level of awareness about the need to have **preventive dental examinations** is exceptionally low, but another barrier is the high expense (price) for dental health services * The identified issue with **charging** the women for examinations performed by their **general gynaecologist** still remains *** Out-of-pocket payments for prescription medicines**, including for COVID, has been identified as an exceptional burden for the Roma women, as a category of people at the greatest socio-economic risk
Accessibility and discrimination	(only concerns those Roma women which are not in the group of women with disabilities) * Between 92% and 98% of the **Roma woman have no feeling of being discriminated against**when using primary health care from the different medical professions, which speaks in favour of the professionalism of general practitioners from an ethical point of view * More than 90% of the **Roma women have positively assessed the physical accessibility** of the general practitioners' medical offices as well as the availability and understandability of the **information** received	* 23% – 37% of the survey participants feel discriminated against when seeing their chosen primary care providers in the different medical professions * 50% – 57% believe that the premises of the chosen primary care providers in the different medical professions are not accessible or are partially accessible; the issue of a basic **physical accessibility** of the medical offices was identified even in the public health facilities (some of the polyclinics operating as part of the public health-care system); * For 45% – 56% of the women, the **information** they receive from their chosen primary care provider in different medical professions is not produced in an accessible and understandable format or is only partially understandable * Only 40% of women with disabilities are aware of their right to **adequate adaptation** of the health facility, and only 12%, or 18% have requested this from their general practitioners	

Area Identified	Positive results	Area Identified weaknesses and challenges	
		Women with disabilities	Roma women
COVID-related health services	* The rate of **vaccination against Coronavirus** with at least one dose of the vaccines is higher than that of the general population * The treatment at, the level of discrimination by, and the accessibility of the **vaccination points** were scored highly * The treatment by the staff employed in the **general practitioners' medical offices** when being treated for COVID was scored highly by the women from the target groups *** 87% of the women with disabilities underwent the entire COVID treatment only at their general practitioners' medical offices** *** The practice of asking money** from women either for a free COVID testing appointment or for making a vaccination appointment in the public health facilities **was not recorded**	* This research, too, confirmed the disturbance in the usual dynamic of **examinations by chosen primary care providers** during the COVID crisis, with dental examinations proving to be affected the most * As many as 25% of women with disabilities that participated in this research have neither seen nor otherwise contacted their chosen primary care provider during the COVID crisis, and only 9% said they used to see their doctors as per usual * People with disabilities who are **deaf or hard of hearing** cannot use the benefit from the possibility to contact their general practitioners by telephone, as an exceptionally important element in the primary health care in an **emergency** * A large share (35.4%) of women with disabilities have never done a **Coronavirus test** * Some 45% of women with disabilities were treated for COVID, which is higher than the rate registered for the country *** The treatment at, the discrimination by and the accessibility** of the health facilities where women with disabilities did their COVID tests and the hospitals where they were treated for COVID were scored with a medium score	* This research, too, confirmed the disturbance in the usual dynamic of **examinations by chosen primary care providers during the COVID crisis**, with dental examinations proving to be affected the most * As many as 20% of Roma women that participated in this research have neither seen nor otherwise contacted their chosen primary care provider during the COVID crisis, and only 11% said they used to see their doctors as per usual * Large share (45.5%) of the Roma women have never done a **Coronavirus test**
Other findings	**internet**	* 15% of the respondents have higher **education**, and 6% have no education; majority of those holding a university degree come from the targeted population with physical disability * 58.5% of women with disabilities **earn their own income**, and from those who do not have their own income, the largest is the share of women that live with their parents who generate income	* Only around 5% have completed higher **education**, and as many as 20% of the respondents have no education at all * Some 40% work and **earn their own income**, including those that have a job, but which are not registered as employed

03 WHAT NEXT?

– recommendations for the various social stakeholders

The research revealed the need for further activities by different social stakeholders, that will be aimed at achieving an improvement in several key areas for the Roma women and women with disabilities:

1. Promoting the preventive health care habits of women

2. Reducing the financial burden of women for their health care and combating corruption

3. Improving the accessibility of health care and the level of information of women

One set of measures that needs to be applied in the future are measures that should be aimed at improving the system in general. The research indicates that these systemic activities will also affect, to a great extent, the Roma women and women with disabilities.

In addition to these, what is exceptionally important are the expertise and the commitment of all stakeholders in defining and implementing specific measures and activities that will reflect the particular needs of the target groups, taking account of their particular vulnerabilities.

Below are specified measures and activities proposed through an inclusive process by representatives of three groups of social stakeholders – healthcare workers, civil society sector and institutions. The results from the field research supported the justification of what was proposed. The implementation of these measures and activities is expected to have a positive impact in the short and middle run on achieving one or more of the objectives specified above.

Measure	Activity	Implementing and involved parties	Objective to be achieved
Encouraging and structuring preventive activities by chosen primary care provider / Improving the access to information	Changing the method of inviting the patients to examinations by mail, which is ineffective and prone to logistical problems, to inviting the patients to examinations electronically (by email) or with a text message (mobile telephones were said to be used by all respondents, and a significant majority of the target group also uses internet)	MH / EHD HIF Chosen primary care providers	1.
	Encouraging the communication through video calls between the chosen primary care providers and their health insurance holders who are deaf and hard of hearing, together with organising trainings on sign language for the chosen primary care providers	Civil society sector Chosen primary care providers	1. 3.
	Developing promotion materials related to prevention protocols on the primary health care level, also prepared in an easy read format format and in sign language	Civil society sector Chosen primary care providers PHI	1. 3.
	Workshops in high schools on health education / prevention	Chosen primary care providers Civil society sector PHI / PHC Local self-government	1.
Increasing the percentage of Roma women and women with disabilities who have a general gynaecologist	Raising the awareness and education about the recommended (preventive) examinations related to reproductive health, but also about what constitutes a rational request during medical examinations pursuant to evidence-based medicine	Chosen primary care providers PHI Civil society sector Local self-government	1. 2. 3.
	Improving the standards on physical accessibility of general practitioners' medical offices	MH AQAHI Chosen primary care providers	1. 3.
Enforcing the right to accessibility and protection against discrimination	Including the legal instrument of adequate adaptation in their policies and applying this instrument	Health facilities	3.
	Improving through training of the level of information and education of people with disabilities and introducing them to their rights, such as the right to adequate adaptation, health rights etc.	Civil society sector MLSP PHI	3.
	Organising trainings for chosen primary care providers on approaching to and communicating with people with different types of disabilities, alternative possibilities of ensuring physical accessibility (pre-assembled ramps, continuous track etc.)	CSOs working with people with disabilities, including people with different types of disabilities	3.
	Mapping though field activities of the level of accessibility of all facilities in the primary healthcare system – health centres and general practitioners' medical offices; the mapping will serve as the basis for further initiatives to all relevant institutions	MH PHI Civil society sector	3.

Measure	Activity	Implementing and involved parties	Objective to be achieved
	Ensuring the cooperation between civil society organisations aimed at delivering trainings and free legal aid for filing complaints with the Office of the Ombudsman and the Commission for Protection against Discrimination, and also initiating court proceedings in response to the violation of the right to accessibility and protection against discrimination	Civil society sector	3.
Facilitating the access to health insurance and reducing the administrative burden for the health insurance holders, and reducing the need for assistance from third parties	Conducting an information access campaign related to health insurance; adapting the information about health insurance in an easily understandable format and in sign language	HIF MH / EHD	3.
	Enhancing the institutional interconnectivity of the public institutions' information systems	HIF CRMO, MOI, MLSP etc.	3.
	Combating the unlawful charging of the health insurance holders in the process of registering for health insurance by empowering and educating the Roma women and women with disabilities, and the general population, too, on how the documents are to be filled out, and ensuring the right to receive this service free of charge from the Funds employees	HIF Civil society sector	2.
Eliminating all the barriers in the process of realising the disability-based entitlements	Providing completely free services	MLSP and SWCs HIF	2.
Revising the payment policies for prescription medicines dispensed in pharmacies and for dental services	Exempting the women at special socio-economic risk from co-payment for prescription medicines and certain dental services	HIF MH	2.
	Accelerating the process of expanding the Positive List with new prescription medicines dispensed in pharmacies	MH HIF	2.
Combating the corruption in the healthcare sector	Including an anti-corruption chapter in the healthcare strategy	MH	2.
	Educating the women about how to identify the corruption in the healthcare sector and about the available mechanisms to report the corruption	Civil society sector SCPC	2.
	Regular risk assessment of healthcare sector corruption and monitoring the achievements in this respect	MH Civil society sector	2.
Monitoring the indicators of access to primary health care for women from the vulnerable population groups, such as the Roma women and women with disabilities, and correspondingly raising the alarm	Developing a national indicators framework with methodology; continuous collection of information about the trends and the current tendencies of the results and their clear, transparent and continuous dissemination to all stakeholders	Civil society sector PHI	1. 2. 3.

Legend:

AQAHI – Agency for Quality and Accreditation of Healthcare Institutions
CSO – civil society organisations
Institute for Public Health - IPH
MOI – Ministry of Interior
MH – Ministry of Health
MLSP – Ministry of Labour and social Policy
CRMO – Civil Registers Management Office
EHD – E-Health Department
HIF – Health Insurance Fund
SWC – social work centres

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Закон за заштита на правата на пациентите

Закон за здравствената заштита

Закон за здравственото осигурување

Закон за спречување и заштита од дискриминација

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