





Implementation of the National Roma Integration Strategy and Other National Commitments in the Field of Health

SLOVAKIA

A multi-stakeholder perspective report on 2005-2014 developments

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CONTENTS

| ACR | ONYMS | 5 |
|------|--|----|
| EXE | CUTIVE SUMMARY | 6 |
| 1. | INTRODUCTION | 9 |
| 2. | GENERAL INFORMATION ABOUT ROMA IN SLOVAKIA | 11 |
| 3. | DATA ON ROMA HEALTH | 14 |
| 3.1. | Roma Mortality Rates | 14 |
| 3.2. | Self-Assessment of Health Status | 15 |
| 3.3. | Chronic Illnesses and Infections | 17 |
| 3.4. | Limitations in Daily Activities Caused by Health Problems | 19 |
| 3.5. | Vaccination Rates | 21 |
| 3.6. | Maternal and Reproductive Health of Romani Women | 21 |
| 4. | ACCESS TO HEALTH-CARE SERVICES | 24 |
| 4.1. | Legal and Policy Framework | 24 |
| 4.2. | The Health-Care System in Practice | 25 |
| 4.3. | The Health-Care System and the Marginalized Roma | 27 |
| 4.3. | Spatial and Financial Accessibility of Health-Care Services | 29 |
| | 2. Experiences and Perceptions of Discrimination on the Grounds of Ethnicity and der | |
| 5. | ROMA SPECIFIC GOVERNMENTAL POLICIES | |
| | Policy Developments in Slovakia | |
| | Revised Action Plan of 2011 and NRIS of 2012 | |
| 5.2. | | |
| 5.2. | | |
| 5.3. | Health Measures Addressing Roma Marginality implemented since 2011. | |
| | lementation of the Revised Action Plan | 48 |
| 5.3. | 1. Data Collection | 48 |
| | 2. Preventive Care with Specific Focus on tackling Infectious Diseases and increas cination Rates | _ |
| | 3. Improved Hygiene, Disinfestation, Disinfection and Monitoring of Garbage ection, Reduction of Environmental Risks | 49 |
| 5.3. | 4. Access to Drinking Water | 50 |
| 5.3. | 5. Improved Access to Basic, Emergency, and Specialized Health-Care Services | 50 |
| 5.3. | 6. Training of Health-Care Personnel | 52 |
| 53 | 7. Reproductive and Sexual Health | 52 |

| 6. EXAMPLE OF GOOD PRACTICE – HEALTH MEDIATORS | 55 |
|---|------------|
| 6.1. Background Developments – KARI and PHARE Programs | 55 |
| 6.2. Healthy Communities Program | 59 |
| 6.2.1. Programme Assessment | 66 |
| 6.2.2. Future of the Programme | 67 |
| 6.2.3. Conclusions | 68 |
| 7. CONCLUSIONS | 69 |
| REFERENCES | 73 |
| APPENDIX – the Use of EU Structural Funds for Roma Health | 7 9 |

ACRONYMS

ACEC The Association for Culture, Education and Communication

ECHR European Court of Human Rights

EU European Union

EU SILC The European Union statistics on income and living

conditions

FRA Fundamental Rights Agency of the European Union

HP MRC EU Structural Funds' Horizontal Priority – Marginalized Roma

Communities (HP MRC)

KARI Krajská asociácia rómskych iniciatív (Regional Association of

Romani Initiatives)

ME SR
The Ministry of Environment of the Slovak Republic
MF SR
The Ministry of Finances of the Slovak Republic
MHC SR
The Ministry of Health Care of the Slovak Republic
MI SR
The Ministry of Interiors of the Slovak Republic

MLSAaF SR The Ministry of Labour, Social Affairs and Family of the

Slovak Republic

MRC Marginalized Roma Communities

NRIS The Strategy of the Slovak Republic in Roma Integration

Strategy Until 2020

OGPRC The Office of the Government Plenipotentiary for Romani

Communities

PHA Public Health Authority

Revised Action Plan Revised Action Plan to the Decade of Roma Inclusion

adopted in 2011

UNDP United Nations Development Program

WB World Bank

WHO World Health Organization

EXECUTIVE SUMMARY

This report discusses the health status of the Roma, their access to the health-care system, as well as Slovak State policies that facilitate the inclusion of Roma in the area of health and health care. In particular, the report focuses on the implementation of the Revised Action Plan to the Decade of Roma Inclusion adopted in 2011 (Revised Action Plan), which has become the operative part of the Roma Integration Strategy of the Slovak Republic until 2020 (NRIS), adopted in 2012.

The report finds that poor housing standards in Romani settlements, exposure to environmental hazards, long-term unemployment, extreme deprivation and poverty extracts a toll on the health of Roma – Slovakia's second largest national minority, after the Hungarians. In fact, demographic estimates of life expectancy of marginalized Roma are reminiscent of those of Slovaks in the 1950s. Available quantitative representative data gathered by intergovernmental agencies such as the United Nations Development Programme (UNDP), Fundamental Rights Agency of the European Union (FRA), and the World Bank (WB) in 2005, 2010 and 2011 describe major inequalities between Romani and non-Romani populations. According to these data, the Roma tend to be more often negatively affected in their daily activities if suffering from chronic diseases. Among Roma chronic conditions, the most frequent were cardiovascular diseases, followed by respiratory diseases, joint and bone diseases, disorders of the nervous system, and mental disorders. Compared to 2005, there has been an increase of those who suffered from cardiovascular and respiratory diseases. Poor living conditions further increase the risk of infections and diseases that are almost unknown in the majority population. Maternal and reproductive health of women also deserves more attention from public health authorities. While Slovakia has a low number of unattended births among Romani women, the country has not addressed early pregnancies. Indeed, data showed that young Romani teenagers have lower awareness about contraceptive methods then their non-Romani peers and very limited access to contraception. Their reproductive health choices seem to be constrained both by the expectations of their families and communities, and by a seemingly inaccessible health-care system.

In theory, all Slovak citizens are guaranteed equal health-care protection, irrespective of their ethnic or national origin. However, in reality, health-care equality falls short of the mark. Slovakia's health-care system – similarly to other public sectors such as education – suffers from systemic deficiencies with wide ranging negative impacts. Underfinancing and understaffing, non-commensurate staff workloads, corruption, and doctors' unwillingness to let patients make autonomous decisions about their treatment are the most frequently cited endemic issues. Extreme poverty, spatial segregation, stereotypes, discrimination, and low health awareness make access to health-care services even more burdensome for marginalized Roma.

Since 1992, policymakers have often reduced these complex problems down to the low health awareness and poor hygiene of marginalized Roma. In addition, governments that sought to more comprehensively address health and health-care inequalities experienced by Roma have been confronted with budgetary constraints. Lack of sufficient funding for specific activities is indeed one of the main deficiencies of the Revised Action Plan and the

NRIS. Implementation of these two documents over the last years has also revealed that tasks in the area of health are often assigned to agencies, in particularly to the Office of the Government Plenipotentiary for Romani Communities (OGPRC), that in fact do not have the needed administrative powers, human and financial resources to implement them. The most glaring examples are ensuring access to drinking water and monitoring of health hazards in Romani settlements.

A top down approach in the drafting of policies of the Government of Slovakia appears to downplay the importance of participation of stakeholders at the local level, including Romani civil society. Policies handed down from the ministerial desks risk coming up short and not sufficiently responding to particular needs at the local level. Moreover, policymakers put little emphasis on the need to affirmatively overhaul the health-care system — everything from eliminating ingrained discriminatory practices to ensuring affordability to providing training for health-care professionals to creating a mutually respectful and discrimination free health-care environment for all, including Roma patients.

The last section of this report focuses on the work of health mediators as an example of a good practice. Overview of the developments that led to the current programme – called Healthy Communities and involving almost 200 health mediators – describes the difficulties encountered in its sustainable implementation over the last decade. The current programme, to date the biggest NGO initiative in Slovakia's history, is implemented by *Platform for the Support of Health of Disadvantaged Communities,* and it brings together a variety of non-governmental, governmental, and private actors active in the area of health.

Health mediators can deliver a tangible improvement to preventive, specialized, and emergency health-care services access for marginalized Roma. Health mediators, hired by the NGO, act as agents of control and help to promote positive changes on the ground. During the first few months of the programme Healthy Communities, some municipalities began actively addressing issues of access to water, for example. Moreover, health mediators, recruited from within the Roma living in marginalized locations, have a potential to act as agents of change towards both the health-care system as well as their communities. Close cooperation with health personnel not only seeks to ensure that parents attend preventive check-ups and vaccination appointments with their children, but to empower doctors to grow more sensitive to specific Roma predicaments and precarious living conditions. For instance, they could provide information in accessible language and charge for services rendered in line with welfare payments for those Roma who are dependent on this rather modest income. It appears that the key ingredients for implementing a successful health mediation programme include - along with solid coordination and quality training – recruitment of the Roma mediators from marginalized communities, and ensuring their independence from local municipal structures.

In designing the new 2015–2020 NRIS Action Plan, the report recommends that tasks be assigned to agencies with the necessary administrative powers, capacities, and human resources to implement them. This is especially critical insofar as ensuring access to drinking water, monitoring of waste management, and environmental hazards reduction.

Moreover, policymakers should ensure adequate funding for each of the tasks that requires activity outside the scope of regular agency duties. The health mediation programme deserves both adequate funding and a programme platform that the size of marginalized Romani population in Slovakia requires. In designing the programme, solid coordination, quality training, recruitment of health mediators from marginalized Roma communities, as well as ensuring their independence from local power structures, are the most critical preconditions for the programme's success. Finally, policymakers should also address barriers inherent in access to health care — obstacles that can have disproportionately negative effects on the Roma, in particular due to the far away locations of medical facilities, the prohibitive cost of health-care services, and the generally low health and legal rights awareness among Roma populations. By way of a pertinent example, the practice of Romani women leaving hospitals prematurely after giving birth suggests that many of the conventional health-care practices fail to address the very specific needs of marginalized Roma, above all women. The report recommends a more ethnically and gender sensitive methodology.

1. INTRODUCTION

The present report analyses the status of Roma in Slovakia, inequalities vis-à-vis the non-Romani population, Roma's challenging access to health-care services, and the actions of the Government of Slovakia in response to the particular vulnerabilities experiences by Roma. Specifically, the report focuses on the implementation of the Revised Action Plan, which has become the operative part of the NRIS adopted in 2012.²

In assessing the health status of Roma, the report draws primarily on quantitatively representative data of Romani population gathered by intergovernmental agencies such as the UNDP, FRA and the World Bank in 2005, 2010 and 2011. Given the non-existence of ethnically disaggregated data produced by State authorities, this alternative information provides an avenue for understanding inequalities between Romani and non-Romani populations. Nevertheless, as the authors of these collections recognize, data gathered using the method of self-evaluation may be inaccurate. In this section, the report also focuses on how chronic illnesses and disabilities affect Roma's daily activities. This information may provide a more accurate picture of the current state of affairs. Notwithstanding, the report also draws on several qualitative studies supplemented by interviews with Romani and non-Romani activists working on the ground.

The central puzzle of the chapter devoted to the health-care system concerns its ability to respond to health inequalities experienced by the marginalized Roma. The analysis first discusses the functioning of the health-care system in general terms. Then it looks at additional barriers in accessing health-care system experienced by the Roma caused by a combination of factors, including extreme poverty, spatial and cultural barriers.

Since 1990, policymakers have to an extent recognized the need to address Roma's specific situations with specific policy measures. Accordingly, in its fifth chapter, this report investigates how the numerous strategies employed since the 1990s conceived Roma health issue, as well as relevant interventions. The substantive part of the chapter is devoted to the adoption, preparation, and implementation of arguably the most extensive and ambitious policy documents adopted to date – the Revised Action Plan that is part of the NRIS. The evaluation of current policies is completed by a detailed case study of the only State initiative in this area – the health mediation programme, currently administered under the title "Healthy Communities".

In the final section of the report, a number of findings and recommendations are elaborated to support policymakers in the preparation of the new NRIS Action Plan, replacing the existing Revised Action Plan as of 2015.

The report draws on available quantitative and qualitative data gathered by international governmental agencies, several independent academic anthropological, sociological and demographic studies, desk research of policy documents and of legislation, and interviews with all involved stakeholders, including marginalized Roma, health mediators, Romani and non-Romani human rights advocates, mayors, health-care personnel, and officials working for the Slovak State administration. Additionally, this report was prepared on the

¹ Revised Action to the Decade of Roma Inclusion, adopted by Government Resolution 522/2011.

² National Strategy of Roma Integration until 2020, adopted by Government Resolution 1/2012.

basis of field work (conducted in February 2014 in eastern Slovakia) with particular focus on the implementation of the "Healthy Communities" programme.

2. GENERAL INFORMATION ABOUT ROMA IN SLOVAKIA

Roma form the second largest (after Hungarians) minority in Slovakia. According to official census data based on self-identification, the size of the Romani population amounts to 2 per cent of the overall population (105,738 people).³ According to data based on ascribed ethnic identity gathered through socio-graphic mapping in 2012, 402,840 persons were considered to be of Romani origin. This corresponds to 7.45 per cent of the overall population, given an overall population size of 5,404,322 inhabitants.⁴

The three main Roma subgroups are *Slovak Rumungre*, *Hungarian Rumungre*, and *Vlach* Roma. Approximately 90 per cent of Roma are culturally similar Slovak and Hungarian Rumungre that have been settled in Slovakia for several centuries, arriving sometime in the 14th century. Vlach Roma is thought to be the descendants of Roma slaves arriving in Slovakia in the second half of the 19th century from Romania. Vlach Roma led a nomadic lifestyle until State authorities ultimately banned this lifestyle in the 1950s. Vlach and Rumungre Roma typically differentiate themselves by the clan to which they belong and by the area where they have settled. Moreover, there are salient internal differences based on gender, socioeconomic status, family occupation, housing area, and history of settlement. According to anecdotal evidence, there is no significant number of migrant Roma, EU and/or third country nationals in Slovakia. Accurate and complete data is, however, hard to come by.

According to available State data based on self-identification, the Roma demographic make-up of Roma communities differs significantly from that of the majority, of other

³ Slovak Statistical Office 2011 data. Please note that in public census gathering, it is only possible to declare belonging to one national group, which likely distorts the actual picture of how people feel about their national identity. There has been a slight increase in comparison to public censuses in 2001 (1.7%) and 1991 (1.4%), likely caused in part by the active promotion by minority leaders of the methods – primarily based on self-identification – of redistribution of finances, among other things, for support of minority cultures. For an overview of the argument suggested by some scientists as well as politicians and Romani leaders about the low levels of self-identification, please see, e.g. Jarmila Lajčáková "Advancing Empowerment of the Roma in Slovakia through a Non-territorial National Autonomy", 2010 Ethnopolitics, 9(2) at 176–177.

⁴ Prvé výsledky Atlasu rómskych komunít na Slovensku (First results of the Atlas of Romani Communities in 2013) at 1–3, published by the OGPRC in September 2013. Available from www.minv.sk/?atlas_2013 (2013 Atlas data).

⁵ There is also a very small number of Sinti Roma – a group of Roma who lived for a number of generations in Germany and Austria.

⁶ Anna Jurová "Historický vývoj rómskych osád na Slovensku a problematika vlastníckych vzťahov k pôde", in: Marek Jakoubek and Tomáš Hirt (eds.) Rómske osady na východnom Slovensku z hľadiska terénneho antropologického výskumu (1999–2005) (Bratislava: Nadácia Otvorenej Spoločnosti, 2008) at 132 and 148, Milena Hübschmanova, "Bilingualism among the Slovak Rom" 1979 International Journal of the Sociology of the Language 19 at 36.

Viera Bačová, "Rómska menšina: vznik a charakteristika rómskej menšiny na Slovensku" in: Anna Zeľová Minoritné etnické spoločenstvá na Slovensku v procesoch spoločenských zmien (Bratislava: Veda, 1994) at 33

⁸ Marek Jakoubek and Tomáš Hirt (eds.) Rómske osady na východnom Slovensku z hľadiska terénneho antropologického výskumu (1999–2005) (Bratislava: Nadácia Otvorenej Spoločnosti, 2008). On inequalities caused by gender see, e.g., Quo Vadis Obraz rómskej ženy: kvalitatívny prieskum bariér participácie rómskych žien na verejnom živote (Zvolen: Quo Vadis, 2012).

minorities, and of other developed countries. According to the State report on national minorities, "Roma society's age structure is represented by the so called progressive type pyramid, characteristic of developing countries with a fast population growth rate (combining a high death rate with an even higher birth rate)." There is a large infant and toddler (0–4) group, which accounts for over 14 per cent of the total. Children under 15 make up 39.4 per cent of the Roma, while those over 60 amount to only 3.9 per cent of the population. 10

Data on ascribed ethnic identity, gathered in 2012 and published in the *Atlas of Romani Communities in Slovakia in 2013* indicates a total of 402,741 Roma in Slovakia. ¹¹ Atlas editors specifically use the term Romani concentrations, and divide them among those located at the edges of municipalities, those within municipalities, and those which are segregated. ¹² Most Roma (46.5%) live dispersed among non-Romani population (187,305 persons). Another 23.6 per cent live on the outskirts of cities and villages (95,020 persons), 11.5 per cent live in urban concentrations (i.e. ghettos) within towns and villages (46,496 persons), and 18.4 per cent live in segregated concentrations (73,920 persons). ¹³ Atlas's data indicated there are 803 Roma concentrations spread across 583 municipalities and towns. Two hundred forty-six concentrations are located within municipalities, 324 localities are at the outer edges of municipalities, and 233 form segregated settlements. ¹⁴

The percentage of Roma living in rural areas is higher (63.6%) than in urban areas (36.4%), ¹⁵ and the largest Romani community is located in the city of Košice (18,162 Roma people). The Košice region also has the highest number of Romani concentrations (230). It is followed by the Prešov region (254), the Banská Bystrica region (142), the Nitra region (65), the Trnava region (61), Bratislava and Žilina (19), and the Trenčín region (11). The highest concentration of Roma is thus to be found in the eastern and south-central provinces of Slovakia. ¹⁶

According to Atlas data, a significant number of Roma live in unsuitable dwellings, such as wooden shacks (31,601), or in illegal wooden cottages (29,406 people) with unclear legal titles to the underlying real property. ¹⁷ Out of all the dwellings located in Roma concentrations, only 58.8 per cent have access to public drinking water pipelines. The fewest (45.2%) are is in dwellings located in segregated/isolated Roma communities. Another 23.7 per cent of Romani households use own source of water (well). Fifteen per cent use another sources of water, such as local creeks. 7.2 per cent do not have access

⁹ Data based on self-identification gathered through public census in 2011. Referred in *Správa o postavení* a právach príslušníkov národnostných menšín za rok 2012 podľa čl.4 ods. I 1 bod 1 štatútu splnomocnenca vlády Slovenskej republiky pre národnostné menšiny, at 30.

¹⁰ Ibid. Please note that structure of the Roma disaggregated on the basis of gender has not been published by the Slovak Statistical Office.

¹¹ Alexander Mušinka et al., Atlas rómskych komunít na Slovensku 2013 (Bratislava: UNDP, 2014) at 16, atlas is available online from: www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/socialne-sluzby/atlas rom-kom.pdf

¹² Ibid. at 6.

¹³ Ibid. at 16.

¹⁴ Ibid. at 15.

¹⁵ Ibid.

¹⁶ Ibid.

¹⁷ Ibid. at 45–56.

to drinking water at all (sum may exceed 100% as some dwellings rely on several different sources of drinking water). ¹⁸ Seven hundred eighty-two Romani concentrations (97.4% of the total) have access to electricity, yet only 94.3 per cent of the electrified dwellings actually use electricity. Another five localities are only partially connected to the electrical grip, and within them, only 35.4 per cent of homes use electricity. ¹⁹

¹⁸ Ibid. at 22.

¹⁹ Ibid. at 33.

3. DATA ON ROMA HEALTH

The analysis of Roma health status draws on available data gathered primarily by IOs, NGOs, and limited academic resources. Clinical health data have not been collected since 1999. Relevant State institutions believe that collecting clinical or expert data, i.e. diagnoses made by medical personnel based on ethnicity, would violate personal data protection legislation. However, it is important to note at the outset that data self-reporting data gathered by representative surveys of Romani households by UNDP, FRA and/or the WB likely distort reality. In particular, data on self-assessment of health status appear inaccurate due to a complexity of factors, including low health awareness.

3.1. Roma Mortality Rates

There is no official data on Roma mortality rates. The only available sources are Branislav Šprocha's demographic calculations for localities included in the Atlas of Roma Communities of 2004, as provided below. ²² His assessment covered the period 1996–2009 in communities with Roma population of 75 per cent or more of the total, as well as localities where the number was over 95 per cent, i.e. both separated and segregated communities. ²³

Table 1: Average for 1996-2009²⁴

| Roma male in 70+ localities | Roma male in 90+ localities | National male average |
|----------------------------------|-------------------------------|-------------------------|
| 64.9% | 63.3% | 69.8% |
| Roma female in 70+ localities | Roma female in 90+ localities | National female average |
| 70.3% | 68.4% | 77.8% |

Infant mortality rates according to the same study are two to three times higher in segregated communities than the Slovak population as a whole. The number of deaths of infants under 28 days old accounted for over 50 per cent of the infant mortality rate.²⁵ The data indicates major health status inequalities between the segregated Roma and non-Romani population. However, it is important to keep in mind that these data are demographic assessments, and not exact facts.

²⁰ Zuzana Vallová, "Možnosti sledovania a analýzy údajov o rovnosti v zdravotníckej štatistike" in Alena Kotvanová (ed.) *Dáta o rovnosti v Slovenskej republike* (Bratislava, Equilibria, 2012) at 136.

²¹ Ibid. at 136.

²² Bronislav Šprocha, "Úmrtnosť a zdravotný stav rómskej populácie na Slovensku, 1.časť, 2012, *Slovenská štatistika a demografia*, Vol.22, No.2 at 86–101 and at 91–92.

²³ Ibid. at 91–92.

²⁴ Ibid. at 91.

²⁵ Ibid. at 92–93.

Table 2: Major health status inequalities between the segregated Roma and non-Romani population

| Population | Ratio of infant mortality in % (number of deceased children up until 1 year old to 1,000 live born) | Ratio of neonatal mortality in % (number of deceased infants up until 27 days old to 1,000 live born) | Ratio of post neonatal mortality in % (number of deceased infants from 28 days to 365 days old to 1,000 live born) | Ratio of early neonatal mortality % (number of deceased infants within 7 days after delivery to 1,000 live born) | Index of perinatal mortality in % (number of deceased within 7 days after delivery and stillborn to 1,000 live born) | Index of still born % (number of still born to 1,000 live born) |
|-------------------------------------|---|---|--|--|--|--|
| Boys in 95+ Roma communities | 23.2 | 8.5 | 14.6 | 6.9 | 15.4 | 0.9 |
| Girls in 95+ Roma communities | 21.4 | 9.4 | 12.0 | 5.1 | 17.2 | 1.2 |
| Boys in 75+ Roma communities | 21.7 | 9.5 | 12.1 | 7.3 | 15.0 | 0.8 |
| Girls in 75+ Roma communities | 16.3 | 7.1 | 9.2 | 4.2 | 12.8 | 0.9 |
| Boys for overall Slovakia | 8.2 | 5.0 | 3.2 | 3.4 | 7.5 | 0.4 |
| Girls for overall Slovakia | 6.7 | 4.1 | 2.7 | 2.8 | 6.8 | 0.4 |

3.2. Self-Assessment of Health Status

Likely the first comprehensive study of Roma health prepared by Partners for Democratic Change Slovakia and Fundación Secretariado Gitano in 2009 (PDCS study) on a sample of 657 Roma indicated relatively positive health self-evaluation. According to the study, 20 per cent of adult (over 18) respondents perceived their health status in the past 12 months as very good, 41.2 per cent assessed their health status as good, 29.7 per cent as average, 8.1 per cent as bad, and 0.3 per cent as very bad. Children and youth below the age of 18 perceived their health status better than the adult population. 40.4 per cent reported it as very good, 45.5 per cent as good, 12 per cent as average, 1.5 per cent as

bad, and 0.7 per cent as very bad. Women in all age groups perceived their health status worse than men; however, the gender-based difference was statistically insignificant.²⁶

In terms of mapping ethnic inequalities in health status, more revealing are data based on comparison between Romani and non-Romani populations. Self-assessment data gathered by UNDP in their representative survey of Romani households in 2010 indicate that Roma from segregated settlements enjoy better health than Roma living in separated environment or Roma living in dispersal.²⁷

Table 3: Subjective evaluation of health in the Roma population age 6 + by type of settlement (in %)

| Type of Community/ Health status | very good | rather good | average | rather bad | very bad |
|----------------------------------|--------------|----------------|---------|---------------|-------------|
| Segregated | 21.4 | 50.2 | 14.2 | 6.3 | 3.4 |
| Separated | 22.4 | 44.3 | 14.7 | 8.7 | 3.3 |
| Diffused | 23.1 | 44.0 | 15.8 | 9.7 | 3.9 |
| Roma population | 22.3 | 46.3 | 14.9 | 7.9 | 3.5 |

Table 4: Subjective evaluation of health by the Roma and by the geographically close general population age 15–64 years (in %)

| Population/Health Status | very good | rather good | average | rather bad | very bad |
|---|-----------|----------------|---------|------------|----------|
| Roma | 23.3 | 45.9 | 18.0 | 9 | 3.8 |
| Geographically close general population | 29.5 | 45.7 | 16.5 | 6.5 | 1.8 |

Source: UNDP Survey of Romani Households in 2010 at 90–91.

In terms of differences between Romani and non-Romani data sets, the Roma self-assessment does not correspond to demographic estimates of life expectancy. Roma perceive their health status as being only slightly worse than that of non-Roma. UNDP/WB/EC Regional survey data from 2011 of 16 and over population even indicated that Roma ranked their health status as being superior to that of non-Roma. Six percent of Roma considered their health to be as bad as non-Roma, whereas such evaluation was

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²⁶ Peter Popper, Petra Szeghy, and Štefan Šarkozy, *Rómska populácia a zdravie: analýza situácie na Slovensku* (Partners for Democratic Change Slovakia, Bratislava, 2009) at 29.

²⁷ UNDP, *Report on the Living Conditions of Roma Households in Slovakia in 2010* (Bratislava: UNDP, 2012) at 90. The sample survey focused on the comparison of different Roma living in three types of environments – segregated, separated and diffused – and a comparison of average values among Romani households and individuals with households from the general population living in close proximity to Roma. The selection and the methodology of choosing communities based on the degree of integration drew on the method adopted in the Sociographic Mapping of Romani Communities in 2004 that resulted in Atlas of Romani Communities. The Atlas identified three types of communities: those living dispersed (Roma living dispersed among the majority population); separated (Roma living on a concentrated area within the ambits of a village, insider or its edges) and segregated (Roma living in a settlement hat is distant from the village or separated by a certain barrier). A representative sample of Romani communities included 3,614 persons (35% of them living in segregated communities, 34% in separated communities and 11% living diffused).

reported by 7 per cent of non-Roma. Both Romani and non-Romani women perceived their health status worse than men (7% of Romani women and non-Romani women).²⁸

The phenomenon of the relatively positive Roma self-evaluation, in particularly by those living in segregated environments, can be explained by the higher prevalence of younger age groups among Roma populations in comparison to non-Roma, as well as the relative inability to accurately assess health status or else a lower overall health awareness. A notable finding is that 38.2 per cent of Roma who assessed their health status as "average" in fact suffered from long-term medical problems, while 97 per cent of those who evaluated their health condition as "rather bad", suffered from chronic illnesses.²⁹

The anecdotal recollection presented in an interview with a Roma activist working in the field confirms how self-reporting distorts reality. She noted that the "health status of the Roma in Slovakia is horrible, cardiovascular and oncological diseases are on rise everywhere where I look, allergies and asthma too... drawing from the experience of my family that lives relatively well".

3.3. Chronic Illnesses and Infections

UNDP data gathered in 2006³⁰ and 2010 indicate that rates of self-reported incidence of chronic illnesses among Roma remain lower than in geographically close populations. Nevertheless, the incidence of long-term illness increases with spatial separation or integration.³¹

Table 5: Occurrence of chronic illnesses in Roma population in different groups in comparison to geographically close general population (in %)

| Age Group/ | Segregated | Separated | Diffused | Total | Geographically |
|-----------------|------------|-----------------------|----------|-------|----------------|
| Type | Roma | Roma | Roma | Roma | Close General |
| of Population | | | | | Population |
| 6+ years total | 17.5 | 20.6 | 22.1 | 20.0 | 29.7 |
| 16+ years total | 23.0 | 25.4 | 25.9 | 24.8 | 32.6 |
| 15+ years total | 22.4 | 24.4 | 25.8 | 24.2 | 32.1 |
| 15–64 years | 21.1 | 21.4 | 23.6 | 22.0 | 24.0 |
| total | | | | | |
| 15–54 years | 16.8 | 16.5 | 21.3 | 18.2 | 17.5 |
| total | | | | | |
| | | Generational G | iroups | | |
| 6-24 years | 7.6 | 9.1 | 9.8 | 8.8 | 9.5 |
| 25-54 years | 20.3 | 20.7 | 27.4 | 22.8 | 19.3 |
| 55+ | 72.5 | 75.3 | 64.3 | 71.2 | 57.9 |

Source: UNDP Survey of Romani Households in 2010 at 81.

³⁰ Report on the living conditions of Roma in Slovakia in 2005 (Bratislava: UNDP, 2007) at 32.

²⁸ Source, data set for Slovakia available from http://europeandcis.undp.org/ourwork/roma/show/D69F01FE-F203-1EE9-B45121B12A557E1B#ROMAexplore

²⁹ UNDP 2012, *supra* note 27 at 90.

³¹ Please refer to the methodology of data gathering adopted by UNDP surveys in *supra* note 27.

Survey authors pointed out several factors explaining these phenomena. First, the lower rate of chronic diseases in segregated communities may be the result of overall younger population and higher percentage of children and young people, who generally suffer less from long term health problems compared to adults and the elderly. Second, it is plausible that the interviewed Roma may have misunderstood what a chronic illness was. It is also likely there were differences in understanding between Roma and non-Roma as to the meaning of a chronic illness. Yet another explanation is the reluctance to admit that Roma they suffer from such diseases.

Furthermore, given Roma's overall worse health-care services access (when compared to the general population), their self-reported health status cannot be taken as a stand-alone indicator of their better health.³⁵ While incidence of chronic illnesses among Roma was higher in 2010 than in 2005, the gap between Roma and geographically close non-Roma population remained more or less unchanged.

In 2010, the most prevalent chronic illnesses among Roma were cardiovascular diseases (29.7%), followed by respiratory diseases (14.3%), joint and bone diseases (14.3%), disorders of the nervous system (12.5%), and mental illnesses (10.4%). In comparison to 2005, the number of Roma suffering from cardiovascular diseases had increased by 7.2 per cent and so had the number of those suffering from respiratory illnesses (by 0.9%). By contrast, prevalence of joint and bone disorders had decreased (by 1.6%), as had nervous system disorders (by 4.6%). ³⁶ Significantly more Roma women than men (by 6.5 percentage points) reported having a cardiovascular disease in both surveys (2005 and 2010). Roma men were by 2.9 percentage points more likely to suffer from joint and bone disorders than Roma women in 2005. In 2010 the difference was 6.5 percentage points. In comparison to the geographically close population, there was a higher prevalence of respiratory, mental, oncological, urinary track and genitalia disorders among the Roma population. The most significant difference was found in the case of mental illnesses. While in the general population the incidence rate was at 2 per cent, in the case of Roma it was at 10.8 per cent.³⁷

Overall, comparison of UNDP data gathered in 2005 and 2010 indicate an increase of the number of Roma suffering from chronic illnesses. The gap between Roma and non-Roma remained unchanged. The geographically close population reported higher occurrence of chronic diseases than the surveyed Romani population. Yet, authors of the UNDP study noted that there is a significantly faster growth and occurrence of chronic and long-term illnesses among the Roma. This likely explains the poor living conditions in segregated settlements, lower health awareness, and poor access to health care. According to NRIS, low hygienic standards in Roma communities appear to cause rather high prevalence of

³² UNDP 2012, *supra* note 27 at 81.

³³ UNDP 2007, *supra* note 30 at 32.

³⁴ Ibid.

³⁵ UNDP 2012, *supra* note 27 at 83.

³⁶ UNDP 2012, ibid. at 83; UNDP 2007, *supra* note 30 at 33.

³⁷ UNDP 2012, ibid. at 83.

³⁸ Ibid. at 91.

infectious diseases such as hepatitis and bacillary dysentery.³⁹ While there is no official data to confirm this assessment, the most recent State report on health status of the general population (2009–2011) mentions a locality almost 100 per cent populated by Roma, to be a reported source of bacillary dysentery associated with Shigella sonnei bacteria.⁴⁰ The report further noted an increase in the occurrence of Hepatitis A since 2008, particularly in regions with high shares of segregated Roma settlements. High occurrences were reported in the Košice region (29.1 per cent of cases per 100,000 people) and Banská Bystrica region (15.0/100,000).⁴¹ The highest prevalence was found in the 1–4 age group (35.4/100,000). The report claims that the findings show "recommended vaccination of children living in environment with low hygienic standards in certain regions is used only marginally and does not affect illness rates in the region."⁴²

While there is a steady decrease in the incidence of tuberculosis in Slovakia, the highest prevalence was also found in the Prešov and Košice regions. The incidence in Prešov (13.96/100,000) was almost twice the rate among the general population. In Košice the prevalence rate was at 10.51/100,000.⁴³ In 2011, there was an outbreak of syphilis in the Roma settlement in town of Trebišov, with a total of 59 cases.⁴⁴

Data sets gathered by the 2012 UNDP report indicate that almost 25 per cent of those suffering from a chronic illness (age six and above) receive disability pensions. The highest percentage of disability pension recipients was in segregated settlements (29.7%), followed by separated (11%), and ethnically mixed areas (7%). ⁴⁵ Roma with chronic medical problems claim disability benefits significantly more often than geographically close non-Roma population with similar health problems. ⁴⁶ This may suggest that those living in areas with worse access to health-care facilities are more often diagnosed at later stages of their illness. Remoteness also increases the likelihood of a chronic condition. Moreover, treatment and disability payments cost the State more for those with poorer access to health care.

3.4. Limitations in Daily Activities Caused by Health Problems

Another commonly used indicator of health status is the self-assessed extent to which chronic illnesses limit daily activities. UNDP data sets on 6+ and 15–64 age groups indicate that Roma suffering by a chronic illness tend to be more limited in their daily activities than non-Roma. As the table below shows, Roma are almost twice as limited in daily activities by their chronic illnesses compared to non-Roma. Moreover, Roma from

³⁹ See e.g. in description in NRIS, *supra* note 2 at 35–36.

⁴⁰ Správa o zdravotnom stave obyvateľstva za roky 2009-2011 (Bratislava: Úrad verejného zdravotníctva, 2012) at 35. Available from

https://lt.justice.gov.sk/Attachment/vlastny_material.pdf?instEID=1&attEID=46924&docEID=253424&matEID=5328&langEID=1&tStamp=20120917112625213. A more recent report has not been issued yet.

 $^{^{41}}$ For overall Slovakia, the illness rate was at 7,4/100,000. Ibid. at 37.

⁴² Ibid. at 38.

⁴³ Ibid. at 42.

⁴⁴ Ibid. at 48.

⁴⁵ UNDP 2012, *supra* note 27 at 83.

⁴⁶ Ibid.

segregated environments tend to be limited by their health conditions slightly more often than Roma living in separated or diffused environments.

Table 6: Degree of limitations of daily activities of the Roma population with chronic illnesses – comparison with the geographically close general population (in %)

| Age group/ | Segregated | Separated | Diffused | Roma | Geographically |
|----------------------|------------|-----------|----------|-------|--------------------------|
| type of population | Roma | Roma | Roma | Total | close general population |
| | | Popula | tion 6+ | | |
| Large | 40.8 | 39.3 | 37.0 | 39.0 | 27.0 |
| Limitations | | | | | |
| Limitations | 45.4 | 48.8 | 48.0 | 47.5 | 57.8 |
| but not great | | | | | |
| No | 5.7 | 13.0 | 13.0 | 7.8 | 13.1 |
| limitations | | | | | |
| I do not know | 8.0 | 2.0 | 2.0 | 5.7 | 2.1 |
| Total 6+ years | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |
| Population 15–64 | | | | | |
| Large | 40.0 | 35.4 | 35.3 | 36.8 | 25.7 |
| limitations | | | | | 25.7 |
| Limitations | 45.0 | 54.4 | 49.7 | 49.8 | 57.3 |
| but not great | | | | | 37.3 |
| No | 5.7 | 6.1 | 12.4 | 8.2 | 15.8 |
| limitations | | | | | 13.0 |
| I do not know | 9.3 | 4.1 | 2.6 | 5.2 | 1.2 |
| Total 15-64 years | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

Source: UNDP survey of Romani households in 2010 at 85.

The 2011 FRA Pilot Survey showed somewhat differing results. The FRA, however, used a different methodology than the UNDP when asking about the extent to which people in age group 35–54 were limited in their daily activities due to health problems. (UNDP asked those who suffered from chronic illness whereas FRA asked the general population). According to the FRA survey data, non-Roma (25%) suffers more often in their daily activity due to their health problems than Roma (20%).⁴⁷

Nevertheless, the Partners for Democratic Change Slovakia and Fundación Secretariado Gitano's 2009 study results tend to lean towards the UNDP findings. This survey methodology resembles the one used in the European Union Statistics on income and living conditions (EU SILC data) data, asking respondents whether they had to limit their activity due to a health problem. The PDCS survey asked whether respondents had to limit their activity due to a health condition in the past two weeks, whereas EU SILC data of 2006 asked the entire population in Slovakia about the previous six months. The PDCS

⁴⁷ The situation of Roma in 11 EU Member States. Survey Results at Glance (Luxembourg: European Union Agency for Fundamental Rights, 2012) at 20.

survey indicated that 17 per cent of the surveyed Roma had to limit their daily activities in the preceding two weeks. Limitations were slightly more prevalent among Roma under 18 (19.1%) than among adults (15.5%). Also, more Roma women (19.4%) than men (14.7%) had to limit their daily activities. The 2006 EU SILC survey indicated that 11.1 per cent of the general population's daily activities were seriously affected by a health problem in the past six months. Daily activities of 18.4 per cent of the general population were affected to some extent.⁴⁸

Overall, on the basis of the UNDP data one can argue that likely due to worse access to health-care treatment discussed below in greater detail), Roma are forced to limit their daily activities due to chronic disability more frequently than non-Roma. While FRA's 2011 survey data indicates that Roma less often limit their daily activity due to a health problem, PDCS's 2009 survey points in the opposite direction, in line with the UNDP findings.

3.5. Vaccination Rates

According to a 2011 UNDP/WB/EC survey, Slovakia has relatively high vaccination levels, both among Roma and non-Roma. Perceived vaccination rate (0–6 years) is at 90 per cent among Roma and 91 per cent among non-Roma. Inequalities exist in case of the six and over age group. Whereas 90 per cent of the Roma claimed to be vaccinated, it has been the case of 95 per cent non-Romani respondent communities.

However, it is questionable whether this positive perception corresponds to reality. For instance, interviewers in the 2009 PDCS survey asked their respondents to show them their vaccination cards for seven basic diseases. The average rate of compliance with this request amongst Roma was approximately 60 per cent, while amongst the general population it was almost 99 per cent. ⁴⁹ Similarly, the State report on the 2009–2011 status of health in Slovakia indicates a lower share of vaccination rates than desirable in 80 health-care districts out of 1,291, in particularly in central and eastern Slovak regions with the highest share of Romani children. Among the reasons for the lower vaccination rates, the report cites postponement of vaccination among new-borns against tuberculosis due to low birth weight, frequent migration of Romani children, and parents failing to bring their children to mandatory vaccination appointments. ⁵⁰

3.6. Maternal and Reproductive Health of Romani Women

In terms of reproductive health indicators, Slovakia Roma women have in comparison to other CEE countries relatively low numbers of unattended births (3%) and relatively high access to gynaecological testing (88%).⁵¹ According to the UNDP survey, 93.7 per cent of Roma women claimed they had attended regular medical check-ups during their last pregnancy, and in most cases (95.5%) had been examined by a doctor.

⁴⁸ Popper et al., supra note 26 at 41.

⁴⁹ Ibid. at 50.

⁵⁰ Správa o zdravotnom stave obyvateľstva za roky 2009-2011, supra note 40 at 49.

⁵¹ Dotcho Mihailov, *The Health Situation of Roma Communities: Analysis of the Data from the UNDP/WORLD BANK/EC survey* (Bratislava: UNDP, 2012) at 58–59.

The most common reasons for not attending regular check-ups were low health awareness about pregnancy health related issues, and difficulty in accessing health-care services. Majority of Roma women claimed that check-ups were not necessary as they had no problems (47.7% among segregated women, 30.5% among separated, 55.4% among diffused and 46.5% for the total of Roma women). The second most common reason for not attending check-ups among women from segregated communities (21%) was "no one told me that I had to attend check-ups", followed by "the doctor's office was too far", and "I had no money to cover my travel costs and I was unable to get there" (5.3%). The most common causes for not attending medical check-ups among diffused Roma women were "it was too expensive" and "due to family reasons (caring for children)" (5.3%). ⁵²

Roma women give their first birth significantly earlier than non-Roma women. According to the 2012 UNDP study, 30.4 per cent of Roma women gave birth to their first child before reaching the age of 18 in comparison to the 2.3 per cent of geographically close non-Roma women. Such early births were most prevalent in segregated communities (34.3%). In the age group 14–21, Roma girls gave birth at the age of 17.42 on average, while it was 21 in the case of geographically close non-Roma population in the same age group. Roma women also tend to give birth to more children than non-Roma women. While the average number of children among interviewed Roma women was 3.5, it was 1.5 in the case of non-Roma women.

One of the interviewed long standing Romani advocates of women's rights explains this phenomenon by pointing to culturally determined expectations that constrain reproductive choices of Romani women, particularly those from marginalized environments. She notes "It remains true that a Romani woman is primarily believed to be a mother and a housewife. The cult of motherhood remains, not only in segregated settlements but also in urban ghettos. It is very visible. If a girl above age 23 does not have a child, she is believed to be infertile and unsuitable for a man. Usually the entire community talks about it and begins to ostracize and exclude her. Also, the cult of virginity persists, but not in a sense that a blood stained sheet is displayed...perhaps this is still practiced among Vlach Roma and in the Balkans. But for a girl who "has" a boy, it has to be her first. Boys reject girls that have "had" a boy before. A woman who had more than one partner before is rejected and considered polluted. Consequently, girls often end up being pregnant. Having a baby this early affects their future educational achievements..." Moreover, as she argues "politicians often abuse the marginality of Romani women with sarcastic and harmful comments such as "the uterus is the money making machine of Romani women" or "Romani parents have children only to receive family benefits." Politicians often perpetuate myths and stereotypes about Roma rather than dispelling them."

According to Andrej Belák's 2005 master's thesis in anthropology based on a year-long study of a Romani settlement in central Slovakia, higher social strata families desire to

⁵² Data on gender disparities gathered by the UNDP in 2010 survey that were not included in the final publication, but were provided on request the author of the report.

⁵³ Ibid.

have on average two children, while the actual average number is three. Lowest social strata, he noted, take a more fatalist approach to the issue as one of his respondents noted "it would be easier to have fewer [children] as we have, but you know... as many god gives, you have to take care of them." ⁵⁴

According to the Belák study, the two most frequently used methods of contraception among women living in the settlement was intrauterine device and sterilization. After negotiating with their husbands, approximately half the women after the age of thirty reaching the age of thirty had their IUD device put in. Approximately one quarter of women at older age underwent sterilization (i.e. in their late thirties and early forties). The women recalled this procedure as being supported by State financial incentives: "20-25 years ago, numerous women sought sterilization after having several children since they got money for it. Then [towards the end of the socialist regime] it was free. Now they cannot afford it, it is expensive, so they have started to use DANA (intrauterine device). Poor women from the lowest social strata still relied on traditional means to induce abortion until the end of the first trimester, i.e. lifting heavy stones until complete exhaustion". 55 A human rights lawyer active in reproductive rights concurs, "Romani women often seek DANA but that is more because they are used to it, not necessary because it would be most suitable. And indeed, oral contraception is very expensive for them." A 2011 report prepared by a group of NGOs confirms that poverty is a significant financial barrier for girls and women in accessing contraception.⁵⁶

The quantitative data gathered in the 2005 and 2010 UNDP surveys indicates a slight improvement in Romani women's familiarity with different contraception methods. In 2005 such awareness was low. Only 63.4 per cent of Roma women were aware of different contraceptive methods. The highest awareness rate was among Roma women from integrated communities (67.1%); least aware were women living in segregated communities (61.5%). The contraception awareness increased to 79.1 per cent in 2010, which was slightly higher than in the case of women from the geographically close population (76.7%). The least informed remained Roma women from segregated communities (71.9%). What was rather disquieting, however, was the low degree of contraception awareness among Roma girls (pupils and students) from segregated communities (31.7%), compared to their Roma peers from separated (51.2%) and diffused (52.6%) communities, as well as non-Roma girls from the geographically close population (47.5%). Sequences of the contraception and the contraception awareness among Roma girls from the geographically close population (47.5%).

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⁵⁴ Andrej Belák, *Zdravie očami vylúčených: antropologická štúdia stredoslovenskej rómskej osady,* diplomová práca (Karlova Univerzita: Praha) at 68.

⁵⁵ Ibid. at 69.

⁵⁶ Christina Zampas et al, *Vypočítaná nespravodlivosť: Zlyhávanie Slovenskej republiky pri zabezpečovaní prístupu k antikoncepčným prostriedkom* (Bratislava, Centre for Reproductive Rights, Možnosť Voľby a Občan a Demokracia, 2011).

⁵⁷ UNDP 2007, *supra* note 30 at 36.

⁵⁸ Please see *supra* note 52 and accompanying text.

4. ACCESS TO HEALTH-CARE SERVICES

4.1. Legal and Policy Framework

As in other post-communist nascent democracies, the authors of the Slovak constitution, incorporated in the human rights sections of the new document social, economic, and cultural rights, including the protection of health. Specifically, the Slovak constitution guarantees everyone's right to protection of health. ⁵⁹ The second sentence of the constitutional article, however, limits that universal privilege somewhat. Free health care is provided to citizens on the basis of health-care insurance. The constitutional provision, as interpreted by Ján Drgonec, implies the State's obligation to create a mechanism that allows everyone to access free health care on the basis of health-care insurance. ⁶⁰ In one of the motions for a constitutional review, the Constitutional court had an opportunity to define the "free" health care. According to the constitutional court, free does not mean at no cost. It means that it is offered on the basis of existent health insurance. ⁶¹

According to the valid legislation in Slovakia, both the employer and the employee pay health-care contributions. This also includes those working as independent contractors, freelancers, and the like. The State reimburses compensates health insurance payments for the most vulnerable groups, including registered unemployed, people receiving social assistance benefits (the poor), children and youth until they complete their university studies, parents on parental leave, and/or people receiving disability and/or age pensions. Eleath insurance also covers the price of prescribed medications (excluding, for instance, oral contraception). Emergency services require a co-payment of EUR 1.99 fee. Out of pocket payments are required for transportation by ambulance (EUR 0.07 per 1 kilometre), and EUR 0.66 to get their prescription in the pharmacy. To be provided with health-care service, one needs to present a valid health insurance card.

Slovak legislation guarantees universal access to health-care services to all regardless of their ethnic origin or gender. Gender. Similarly, State measures to protect people's health should equally target all citizens. In 2001, the Government of Slovakia adopted the Charter of Patients' Rights. The charter guarantees, among other things, respect of informed consent, confidentiality with regard to patient data and medical records, and the right to complain and seek remedy for mistreatment by health-care personnel. Patients' rights were later included in paragraph 11 of the Health Care Act. This legislation stipulates that everyone has the right to access health care and that this right shall be guaranteed on a non-discriminatory basis. The act also ensures respect for human dignity, including physical and psychological integrity, access to information regarding one's health status and confidentiality of such information. Monitoring of health-care services, including

 $^{^{\}rm 59}$ Article 40 of the Constitution, Act No.460/1992 Coll. as amended.

⁶⁰ Ján Drgonec, Ústava Slovenskej republiky: komentár, (Šamorín: Heuréka, 2. vydanie, 2007) at 420.

⁶¹ Finding of the Constitutional Court, 38/03 of 17 May 2004.

⁶² Act No. 580/2004 Coll. on Health Insurance, as amended, para 11 sec 7.

⁶³ For an overview of out of pocket payments see e.g. at: www.zzz.sk/?clanok=13619

⁶⁴ Slovakia, Act No. 576/2004 Coll. on Health Care as amended, para 11 (Health Care Act).

⁶⁵ Slovakia, Act No. 355/2007 Coll. on Protection, Support and Development of Public Health, as amended.

⁶⁶ Charter of Patient's Rights, adopted by Government Resolution No. 326/2001 Coll.

⁶⁷ Health Care Act, *supra* note 60, para 11 sec.1, 2 and 8.

observance of patients' rights, is vested with the Health Care Surveillance Authority.⁶⁸ However, this agency does not gather data on complaints filed on ethnic grounds. Slovakia also has a rather solid antidiscrimination legislation ⁶⁹ that followed the *acquis communautaire*. NGOs, however, often argue that the law lacks institutional structures for its implementation, including not functioning equality body.⁷⁰

4.2. The Health-Care System in Practice

Since the fall of Communism, Slovakia has moved from a centrally planned, universal coverage health-care system financed directly from the State budget to an insurance-based universal model, known as Bismarck or German model. ⁷¹ Contributions from employers, employees, the voluntarily unemployed, and the State in the case of some categories of vulnerable individuals are pooled by health insurance funds. Currently there are three health insurance companies. One of them, Všeobecná Zdravotná Poisťovňa, is wholly owned by the Ministry of Health Care (MHC SR), i.e. the State. ⁷²

One of the fundamental problems of health-care systems in post socialist countries is their insolvency. A study of UNDP in all post socialist countries, including Slovakia, notes the widening "gap between health system liabilities and revenues, leading to long-term structural problems that contribute to structural deficits. The structure of health expenditures is another common problem that contributes to the health system deficits. Those costs are overburdened by disproportionate share of inpatient care, at the expense of preventive care as well as outpatient and pre-hospital care. In all countries, citizens bear some out-of-pocket expenditure for health services." 73

Moreover, health-care ranks among the most corrupted public sectors. According to the January 2012 Transparency International Slovakia quantitatively representative study, people viewed health-care services as the sector most affected by bribery (61%). Health care was followed by the judiciary (52%) and ministries in general (51%). Over the last couple of years, 26 per cent of interviewed respondents gave a gift or a bribe to health-care personnel, often to express gratitude (19%) or to ensure timely treatment (14%).⁷⁴ In its *Strategic Plan for Fighting Corruption in the Slovak Republic*, ⁷⁵ the government focuses largely on the insufficient capacity to provide specialized health-care services as a major cause of corruption practices. In addition, questionable relations between doctors

⁶⁸ Act No. 581/2004 Coll. on Health Insurance Companies and Surveillance in Health Care, as amended.

⁶⁹ Act No. 365/2004 Coll. on Equal Treatment in Certain Areas and on Protection against Discrimination and Amendment of Act No. 308/1993 on the Establishment of the Slovak National Centre for Human Rights.

⁷⁰ Civil Society Monitoring Report on the Implementation of the National Roma Integration Strategy and Decade Action Plan in 2012 in Slovakia (Budapest: Decade of Roma Inclusion Secretariat, 2013) at 29 and 35-38 (Civil Society Report) at 29 and 34–36.

⁷¹ Mihailov, *supra* note 51 at 8.

⁷² See more details at the insurance company website at: www.vszp.sk/o-nas/zakon-c-211/2000-z z/.

⁷³ Mihailov, *supra* note 51 at 9 and sources cited therein.

⁷⁴ Percepcia korupcie na Slovensku, Prieskum verejnej mienky pre Transparency International Slovensko (január 2012). Available from www.transparency.sk/wp-content/uploads/2010/01/FOCUS_Sprava-pre-TIS jan20121.pdf

⁷⁵ Strategic Plan for Fighting Corruption in the Slovak Republic, 8. Available from www.vlada.gov.sk/data/files/2240 8518.pdf Adopted by Government Resolution No. 517/2011.

and pharmaceutical companies have been evaluated as another significant risk for non-transparency. ⁷⁶

A rather intriguing view of deficiencies in the health-care system generally, and specifically with respect to Roma, is offered in the anthropological study of Belák, commissioned by the World Health Organization (WHO) and published in 2014.⁷⁷ Belak's report is based on 20 in-depth interviews during a three month period spent visiting and observing the work of health-care practitioners in the two regions with the highest concentration of Romani population. ⁷⁸ His study identified the following general limitations in ambulance and clinical practices:

- 1. The *lack of general public's appreciation of work of particularly less qualified ambulance and clinical practitioners*. Health-care personnel remuneration is too low, (i.e. below national average). In addition, the personnel frequently encounter arrogant and rude behaviour from their patients. Also, superior and more qualified health practitioners often treat nurses especially in peripheral State owned hospitals with disrespect. Finally, since salaries of nurses and ambulance personnel are very low, they are often forced to work significant amounts of overtime.⁷⁹
- 2. A growing number of ambulance staff and clinical practitioners are forced to engage in counselling and welfare workload in tasks beyond the scope of their profession. For example, ambulance staff carries out more than emergency treatment. The health-care practitioners are required to take care of anxieties, recurring psychosomatic states, crises of neglected chronic conditions, addressing patients' socioeconomic issues such as unaffordability of medication, clothes or sanitary conditions, and the like.⁸⁰
- 3. The quality of health-care services suffers further from *notorious understaffing* and underfinancing of health-care professionals at all levels. This is particularly the case at peripheral hospital and health-care facilities where the majority of marginalized Roma reside.⁸¹
- 4. Health-care personnel also exhibit *low levels of solidarity and poor interpersonal communication*, with the exemption of small privately owned practices in lucrative locations. Belák has identified hostility and lack of loyalty as being typical in most clinical practitioners.⁸²
- 5. Moreover, there is a growing general public ignorance regarding health. Belák, for instance, notes that ambulance staff and clinical practitioners are asked to

⁷⁶ Ibid. at 12–13.

⁷⁷ Andrej Belák, *Health-System Limitations of Roma Health in Slovakia (qualitative study report)* (Bratislava: World Health Organization, country office Slovakia, 2013) (Belák a).

⁷⁸ Ibid. at 12.

⁷⁹ Ibid. at 17.

⁸⁰ Ibid. at.17.

⁸¹ Ibid. at 18.

⁸² Ibid.

perform procedures without clinical indications, such as prescriptions of antibiotics.⁸³

6. Finally, an increasing crisis of confidence in own expertise among health-care practitioners represents another worrying trend. While being confronted by marketing pressures from pharmaceutical companies, contradictions in expert options, general practitioners and paediatricians in particular are finding it difficult to make decision regarding treatment.⁸⁴

These general limitations inherent in the Slovak health-care system affect negatively all patients, including Roma. For instance, extreme workload and the lack of public appreciation of the value of the work performed by certain medical practitioners may even have a disproportionate impact on Roma, considering they are among the poorest, most vulnerable, and also the least popular minority in Slovakia.

4.3. The Health-Care System and the Marginalized Roma

In theory, Roma are guaranteed equal access to health-care services. For members of vulnerable social groups, i.e. children, pregnant women, long term unemployed, health insurance is covered by the State. Slovakia's health insurance reasonably well covers the Roma and ensures possession by the Roma. Health insurance cards are preconditions for accessing health-care services, with the only exception of emergency health-care services, which are not contingent on valid health insurance cards. While there is no official quantitative data, UNDP/WB/EC representative studies from 2011 indicate that there is no significant disparity in health insurance coverage between Roma and non-Roma (97% for Roma and 98% for non-Roma). 86

Nonetheless, despite this favourable context, the health-care system's deficiencies identified by Belák impact all patients, most of all those in difficult socioeconomic situations. For instance, low quality of health care and clinical services contributes to existing Roma prejudices about non-Roma, as well as Roma's self-segregating tendencies. It can also be argued that paying for health-care services out of pocket, either because of co-payment requirements or due to corruption, has a more disproportionate impact on Roma – not because of ethnicity but rather due to social status and poverty.

In addition, Belák has identified several Roma-specific limitations in ambulance and clinical practices:

1. Both written and informal (implicit) ambulance procedures appear less functional for segregated Romani patients. "Ambulance and clinical practitioners often find themselves unable to obtain useful anamneses or securing even the most basic patient cooperation with respect to diagnostic, therapeutic, and administrative

⁸³ Ibid.

⁸⁴ Ibid. at 19.

⁸⁵ Health Care Act, *supra* note 64, para 2 sec 3.

⁸⁶ Mihailov, supra note 51 at 36.

tasks." ⁸⁷ Complications range from the inability to understand and sign informal consents to unnecessary damage to health, including withdrawal from life-saving therapeutic treatment. These specific challenges can be addressed only by practitioners with a long standing experience and willingness to devote extra time and effort. ⁸⁸

- 2. There is an *intensifying trend in aggressive Roma specific behaviour*, typically involving middle-aged and teen-aged segregated Roma of mid-to high socioeconomic standing. Belák notes that such behaviour is "much more common and specific in its forms." ⁸⁹ It includes extreme verbal abuse, including allusion to sexual perversity, allegations of discrimination, blackmailing with self-harm or direct physical attacks. This behaviour is most frequently directed towards professionals of lower qualification following asymmetries in authority. Often it evolves around what Belák calls "peaks of Roma collective conflicts" ⁹⁰ related to welfare payments and often involving alcohol consumption. ⁹¹
- 3. Segregated Roma's specific health situation presents another set of counselling and welfare needs beyond the scope of health-care professions. This includes dealing with socioeconomic issues of teenage and productive age segregated Roma, conflict resolution, unaffordability of medications, lack of transportations means, child neglect, anxieties among elderly Roma, high cost of food, and recurrent neglect of personal hygiene. 92 "Moreover, Belák argues that non-Roma patients in analogous situations typically exhibit much less related practical knowledge and self-confidence, better fitting the "helping-the-victim" character of the situation." 93
- 4. Worst off segregated Roma in comparison to the absolute majorities of Roma, non-segregated Roma, and better off segregated Roma *exhibit consequences of long term health neglect of personal hygiene* too difficult for the health-care personnel to deal with. Lack of sanitary infrastructure in fact increases the risk of infection in health-care premises.⁹⁴
- 5. Finally, there are instances of truly racist behaviour, including unwillingness to treat Roma patients and derogatory comments made by health-care staff. These discriminatory behaviours, however, are often the actions of psychologically troubled practitioners, and are generally denounced and rejected by other medical personnel as well as the Roma themselves. More frequently, Belák has identified, prejudice shared by health-care professionals leads to inferior quality

⁸⁷ Ibid. at 20.

⁸⁸ Ibid.

⁸⁹ Ibid.

⁹⁰ Ibid. at 21.

⁹¹ Ibid.

⁹² Ibid.

⁹³ Ibid.

⁹⁴ Ibid.

of medical services based on previous frustrating experience with them or other Roma.⁹⁵

In addition to the lower overall quality and efficiency of health services, these factors have a disproportionately negative impact on Roma health, leading even to incidences of premature death. Roma beliefs about the low quality of services contribute to the prejudices shared by Roma and deepen the existing self-segregation practices. Generally, described health-care deficiencies, including the lack of solidarity among practitioners and the unresolved split of ambulance and clinical practices lower the quality of services provided to Roma even further. Finally, the lack of expertise in health research, both mainstream and Roma-specific, the lack of reliable data, public health subordination to political and economic regimes, and lack of systematic evaluation of the failures in providing adequate health care to Roma all contribute to the dire state of Roma health today. Figure 1.

4.3.1. Spatial and Financial Accessibility of Health-Care Services

Remoteness of Romani concentrations and settlements creates another significant barrier in accessing health-care services, especially when combined with poverty. According to the most recent quantitative data from the Atlas of Romani Communities 2013, the average distance from Romani dwellings to the nearest health-care provider ranges from five to ten kilometres. 98 This distance means that 92 per cent of Roma have access to health services, as defined by the 2011 UNDP/WB/EC Regional Survey. A 2013 qualitative UNDP study with a sample of 200 further specified that people typically reach the doctor's office by foot in case of distances of up to one kilometre (71%). When the doctor's office is further away (up to five kilometres away, or from six to twenty kilometres away), they use public transportation (36% and 59% respectively). 99

Nevertheless, visits to doctors or hospitals, including relatively modest travel costs for public transportation may present a major financial burden for extremely poor families. ¹⁰⁰ Indeed, according to the 2010 UNDP survey, 17.7 per cent of Roma with health problems did not seek medical care due to financial problems. In the case of geographically close non-Roma population, this percentage was only 1.4 per cent of the sampled population. ¹⁰¹ Non-Romani patients tend to spend more on costs related to seeing a doctor. For instance, one fifth of the surveyed Roma paid EUR 4–6 and one third reported paying more than EUR 10. Patients from geographically close non-Roma population paid on average EUR 18.39. ¹⁰²

⁹⁵ Ibid. at 22.

⁹⁶ Ibid. at 23.

⁹⁷ Ibid. at 35–36.

⁹⁸ Data provided on request by Daniel Škobla, poverty officer at the UNDP to the author of the report in January 2014.

⁹⁹ Jarmila Filadelfiová et al. *Situačná analýza vybraných aspektov životnej úrovne domácností vylúčených rómskych osídlení* (Bratislava: UNDP, 2013) at 27.

¹⁰⁰ UNDP 2012, *supra* note 27 at 89.

¹⁰¹ Ibid. at 87.

¹⁰² Ibid.

More significantly, financial situation frequently prevents Romani patients from obtaining all prescribed medications. As one of the interviewed doctors confessed "I often find scrunched recipes that I have written out in the waiting room of my office or next to the pharmacy. I know that they simply did not have the money to buy the medication." The 2013 UNDP qualitative study also described numerous situations wherein patients suffering from chronic diseases were simply unable to purchase their medications. As one of the respondents recalls, "My mother has frequently been to the doctor's office. Ophthalmologist treats her because she suffers from high eye pressure. Always on the eight of the month, she travels by bus to the doctor. The doctor treats her well. My mother has known the doctor for several years already. The problem is finances. When she gets her recipe, she is not always able to purchase the medication." ¹⁰³ As one of the interviewed Romani activists concurs, "it is not that people do not buy cough syrup, but medications to treat serious conditions such as high blood pressure".

Failing to follow the prescribed treatment is likely to result in worsening of the patient's condition, perhaps even requiring emergency intervention at the end. "It was my wife who last time went to the gynaecologist. She walked to the ambulance, but she was unable to purchase the prescribed medication. It cost 16 euros. No one could loan her money, so finally she ended up with major cramps in the hospital. She stayed in the hospital where she was treated only as a gypsy." ¹⁰⁴

Available quantitative data confirms these observations. According to the 2012 UNDP study, only 63.7 per cent of Roma from segregated settlements purchased all prescribed medications after seeing a doctor. In the case of Roma living in ethnically mixed areas, the rate was 77.7 per cent. The most common reason for not purchasing the medication was its cost. ¹⁰⁵ The 2011 UNDP/WB/EC Regional survey data indicate that 48 per cent of Roma did not have access to essential medications, while it was only 19 per cent in the case of non-Roma. ¹⁰⁶

Roma poverty affects their access to reproductive health services; as one of the interviewed women in the UNDP study recalled, "I was pregnant and I wanted to go do an abortion [she already had four children aged 8 to13]. I was two months pregnant. We did not have the money, as I was supposed to pay 250 euros [for the abortion]. Since I was unable to find anyone to loan me that kind of money, I was forced to keep the child. Now I am in my fifth month and after eight years, I will be again giving birth, although I did not want to have a child in such poverty." 107

Poor Roma often cover unexpected medical costs by loans from different sources – close relatives, social field workers, and even loan sharks. ¹⁰⁸ Roma frequently reported "hiring" a car from a relative or someone from the concentration – frequently a euphemism for making payments to predatory lenders. In some situations, the loan had to be paid back

¹⁰³ Filadelfiová et al., *supra* note 99 at 35.

¹⁰⁴ Ibid. at 36.

¹⁰⁵ UNDP 2012, *supra* note 27 at 87–88.

¹⁰⁶ World Bank survey source data, *supra* note 28.

¹⁰⁷ Filadelfiová et al., *supra* note 99 at 36.

¹⁰⁸ Ibid. at 37.

by manual work.¹⁰⁹ Sometimes, people simply resign themselves to a life without medical treatment as they realize they would not have finances to purchase medications. As one of the respondents confessed, "We do not go to the doctor's office very much. This is not that we would not be sick, but simply we are unable to purchase medication, then for what would we go there?! If someone goes to the doctor, it is me. I suffer from permanent cough. My father had something with his lungs.... That's life."¹¹⁰

Incomes and Expenses of excluded Romani households

Poverty undoubtedly poses a critical barrier not only to health-care access, but also the ability to lead a healthful lifestyle, subsuming basic needs such as water, shelter, and food. The structure of marginalized Roma incomes and expenses is well documented in one of the UNDP empirical studies that followed up on the 2010 quantitative study of Romani households. Researchers focused on incomes and expenses of 100 Romani households selected on the basis of two criteria, the first of which was employment. That is, 80 per cent of households were selected from the pool of families without any employed family members, and 20 per cent from those with at least one working member. The sample was furthermore divided on the basis of number of dependent children – 20 per cent who had no children, 33 per cent with 1–2 children, 33 per cent with 3–4 children, and 27 per cent with five or more). ¹¹¹

Average monthly household income for Romani families was EUR 597.60. That works out to EUR 112.3 per person per month. Social welfare payments accounted for 63.7 per cent of their income, employment wages constituted 26.50 per cent, while 2.7 per cent came from some form of enterprise, 1.4 per cent from gifts, and 5.7 per cent from loans. In comparison to statistical data for all of Slovakia, income as well as the structure of incomes differs in case of Romani households. Average income per person in Slovakia is three times higher (EUR 348.95 per month). Among the general Slovak population, social income amounts to 31.5 per cent versus 68.1 per cent from other income. 112 Furthermore, while the highest share (39.5%) of Roma social incomes consisted of material aid benefit (welfare support for the poor), in case of the general population this was from retirement pensions (77.4% of social incomes). On average, the general population receives EUR 86.6 a month in retirement income, while the Roma get only EUR 8.76. The study also found that incomes of excluded Romani households lag behind Slovak average, and are below the poverty line. Even having a single working member of the household does not guarantee an increase of income to the average found in the Slovak population. Having one working member does not suffice to escape poverty, i.e. the state of so-called material need. 113

Romani families with five or more children are most likely to be confronted with extreme deprivation. Their average monthly income amounts to less than EUR 100 per person per

¹⁰⁹ Ibid. at 30–31.

¹¹⁰ Ibid. at 6.

¹¹¹ Jarmila Filadelfiová, *Príjmy, výdavky a spotreba domácností vylúčených rómskych osídlení* (Bratislava: UNDP, 2013) at 9 (Filadelfiová, 2013a).

¹¹² Ibid. at 13-14.

¹¹³ Ibid. at 19.

month in a household, which dramatically increases the risk of being extremely deprived. This means being unable to provide enough food and pay for heating. 114 Indeed, UNDP's 2010 data indicated that 55 per cent of excluded Romani households have experienced situations when they had nothing to feed their children (and 46% have been in the same situation more than once). The absence of food was reported to be most frequently a problem households encountered in segregated settlements (61%). 115 The deprivation increases the risk of Roma falling victims to predatory lending, either from informal usurers or from legitimate companies offering quick loans at interest rate resembling usury. 116

The biggest Romani families (those with five or more members) also have the lowest expense per member for food (EUR 35 a month). On average, food expenses range between 37.6 per cent of their overall monthly (for the biggest families) and 40.2 per cent in the case of the smallest ones (e.g. single parents). The second largest expense (17.5% on average) is used to cover housing expenses, and the third (10.5%) – interest payments and loan instalments. Health-care related expenses on average constitute only 1.7 per cent (EUR 1.81 a month) per family member per month. Excluded Romani households spent on average 7.3 per cent (EUR 7.62) of their income on alcohol and tobacco – the fifth largest expense in family budgets, after food, housing, interest payments, and clothing. 117

The UNDP study confirmed that excluded Romani households do not have the means to ensure adequate and healthy nutrition. In particular, during periods preceding welfare pay dates, Roma families experience absolute poverty marked by hunger. As one of the interviewed health mediators noted, "we have been encountering the problem of parents sending their children to school when they were sick. We found out that the parents did so simply because they wanted their children to be provided meals by the schools." Children whose parents are in material need (e.g. their monthly income is less than socially acceptable and legally defined minimum for survival) have one of their school meals covered by the State. ¹¹⁸

Romani households simply cannot afford to buy fruit, vegetables, or dairy products from their modest income. Food consumed in poor Romani households typically includes high-calorie, low-nutritional value items. ¹¹⁹ As well summed up by a Romani activist, "even if people were aware of what constitutes healthy nutrition, for that little money they simply cannot afford such food."

Financial difficulties were nevertheless only the third most frequent reason for not seeking medical health. Up to 32.8 per cent of Roma and 46.4 per cent of non-Roma did not seek medical help because "it was not necessary." Furthermore, 21.7 per cent of

¹¹⁴ Ibid. at 21.

 $^{^{115}}$ Reproduced in ibid. at 87.

¹¹⁶ Ibid. at 23

¹¹⁷ Ibid. at 48–49.

¹¹⁸ The State subsidy is provided to schools that have at least 50 percent of children from households that are in material need. The subsidy according to Act No. 244/2010 Coll. on Subsidies that are Within Competencies of the Ministry of Labour, Social Affairs and Family as amended, amounts to maximum of EUR 1 a day per child.

¹¹⁹ Filadelfiová et al. supra note 99 at 106.

Roma and 26.5 per cent of non-Roma did not seek medical help because they "waited for the problem to go away." As Belák aptly summarizes in his recent interview, "Roma pay no attention to prevention or to convalescence after their sickness. Girls do not visit the gynaecologist unless they must. Health-care personnel consider it a major success if they convince a mother from a settlement to attend a preventive visit with her child... It is rather frequent that a person from a settlement is in an emergency situation requiring special treatment. He or she arranges a visit to a specialist office, often using an ambulance or a helicopter. But a Roma, who has never been further than 20 kilometres from the settlement in her or his life, is absolutely unprepared for anything ranging from language to "gadje" [non-Romani] meals. He or she gets scared and would rather sign a refusal of treatment to return to the safety of his or her home. After several months he or she dies as a result of not-treatment. There are a lot of examples like this, and the entire problem does not formally exists – indeed hospitals are here everywhere for everyone. This is the tragic consequence of the system's deficiency. On the one hand it is a result of extremely strong social exclusion and on the other hand of lack of cultural competencies of healthcare facilities and their inability to temporarily address these barriers." 120

Indeed, quantitative data also confirms that Roma adults are significantly less likely than non-Roma to attend regular check-ups or to see a doctor if they have a health problem. The 2011 UNDP/WB/EC regional survey indicated that only 43 per cent of Roma attend dental check-ups, while 73 per cent of non-Roma do, and that 40 per cent of Roma and 59 per cent of non-Roma attend X-ray, ultrasound or scan examinations. Cardiovascular related check-ups are attended by 40 per cent of Roma and 59 per cent of non-Roma.¹²¹

4.3.2. Experiences and Perceptions of Discrimination on the Grounds of Ethnicity and Gender

Ethnic discrimination may pose another significant obstacle to Roma health-care services access. As previously mentioned, however, there are no comprehensive surveys or data sets that would map out forms and extent of discrimination in the health-care sector. Available quantitative data from the 2013 situation report suggest that the majority of Roma respondents viewed their most recent treatment by medical personnel as normal (57%), 12 per cent assessed it as excellent, while 19 per cent saw it as lacking. There were several instances where respondents felt being discriminated against on the grounds of their ethnicity. 123

Qualitative UNDP study from 2013 revealed problematic aspects of Roma medical treatment. In recording experiences during their most recent visit to the doctor's office, some patients recollected they had been less favourably treated due to their ethnicity. "My husband had an asthma attack; we went to the emergency room; we paid 2.50 euro...

Rudolf Sivý "Andrej Belák, Skúmal prečo je zdravie horšie: Chyba je aj v systéme", SME, 16 February 2014. Available from http://romovia.sme.sk/c/7105272/skumal-preco-je-zdravie-romov-horsie-chyba-je-aj-v-systeme.html

¹²¹ World Bank source data, *supra* note 28.

¹²² Filadelfiová et al. supra note 99 at 40.

¹²³ Ibid.

The doctors behaved badly towards us, as soon as they noticed we are Gypsies." ¹²⁴ Another mentioned preferential treatment of non-Roma "We were in emergency room in Trebisov (20 km), the wife dislocated a leg. The nurse was unpleasant, didn't take people in order but in the order she wanted. We waited more than three hours. The doctor was good." ¹²⁵

The Romani women's rights activist in her interview personally admitted encountering racism and discrimination in health-care facilities. Marginalized Romani women with whom she kept in touch also recalled discrimination in health-care facilities. She noted: "In our town, it has been a public secret that there is a Romani ward in the hospital." She believed that this practice was the same everywhere, not only in the region that she comes from. "Women who look Romani or come from a "socially excluded environment," as health personnel sometimes refer to them, are automatically placed in separate wards. This practice continues... Some non-Romani women refuse to be in wards with Romani women... it is nothing new, I encounter this all the time".

The interviewed non-Romani women's rights advocate in responding to the issue of ethnic discrimination recalled legal cases concerning the practice of coercive sterilization. She noted, "when gynaecologists testified, statements such as 'those gypsy women do not know how to take care of themselves... When I was in Africa, those African women were kissing my hands and gypsy women should be kissing my hands as well' were not exceptional." She concurred with the Romani women's rights activist on the existence of segregation practices in health care. The Centre for Civil and Human Rights where she works was currently suing the State over such discriminatory practices. In the course of preparation of the legal case, the centre undertook numerous in depth interviews with Romani women, which confirmed the existence of this practice in maternity wards, often "justified" on hygienic grounds by hospital administration.

The interviewed human rights lawyer also noted self-segregation practices among Romani women. She explained: "they (Romani women) simply felt that non-Romani women are keeping their distance." Belák in the course of his master's study in central Slovakia also observed and described similar tendencies. As one of the interviewed Romani women spontaneously stated, she would rather be in a room with any Romani women — even from a very poor settlement — than a gadje woman. "Gadje women would permanently remind you that you are a gypsy. And with ours (women), I can at least talk normally". 126

The human rights lawyer also said that in the course of her practice, she had also seen segregation cases of Romani children being kept separate from other children while in children's hospitals. In addition, Romani parents were disallowed to stay with their children at the hospital, even though that was a common practice normally permitted for non-Romani parents.

¹²⁴ Ibid. at 53.

¹²⁵ Ibid. at 53.

¹²⁶ Belák, *supra* note 54 at 57.

Romani Women Leaving Hospitals after Giving Birth

A significant source of controversy and media attention focus has been the frequent marginalized Romani women's practice of leaving the hospital soon after giving birth, leaving their new-borns behind for a few days. As Belák notes in his master's thesis, this practice has been frustrating health-care personnel for quite some time. In a hospital in eastern Slovakia, medical staff has been trying to reverse this custom. After failing to do so, hospital staff simply decided to lock the Romani mothers in their wards. The hospitals then slowly become used to situations when young Romani women ostentatiously banged their heads on the walls knowing that this would get them outside. Belák explains that for Romani women often feel the need to return home and take care of their husband and older children. As one of the interviewed women in his study remarked "What will my husband do and how would he live there (home)? I have children there and I should be lying here? So my husband should be eating in other households or what?" 128

Similarly, the Romani women's rights activist explains, "women are leaving hospitals after giving birth not because they would want to abandon their children, but because they have other children at home. They are know that their husband would not take care of the children and could not rely on them... it is this fear that compels Romani women to leave, not their carelessness about their newly born babies. They know that babies will be taken care in hospitals while it may be their older children that are in need."

Belák observes that this practice in fact shows a great expression of trust towards the doctor and health-care personnel, while the human rights lawyer pointed to another rationale. In her view, Romani women are often exposed to humiliating and discriminatory treatment, including being forced to sleep on the hospital's floor as there is not enough space in the Romani only maternity wards.

Both human rights lawyer and Romani women's rights activist concur that the State simply fails to take into consideration specific needs of Romani women as well as other women who simply do not want to stay in the hospital for several days after giving birth. If there are no health complications, the lawyer claims, there is not any reason for such mandatory stay. As discussed below, the State has been trying over the last ten years to legislatively penalize this practice rather than accommodate it. The Romani women rights activist notes, "instead of accommodating the specific needs of Romani women by, for instance, creating opportunities for older children to stay with their mother while she is in the hospital, the State simply relies on repressive measures. I believe this is highly discriminatory". The lawyer adds "and the penalty will not solve or change anything."

¹²⁷ Ibid. at 57.

¹²⁸ Ibid. at 57.

¹²⁹ Ibid.

Cases of Involuntary Sterilizations of Romani Women and Regulation of Informed Consent

One of the most troubling violations of Romani women's reproductive health rights have been the instances of involuntary sterilizations of Romani women. Reproductive health and human rights NGOs have, for more than a decade now, been asking the Slovak State to investigate all such cases before and after 1989. The Centre for Civil and Human Rights has successfully litigated three involuntary sterilizations of young Roma women in public hospitals taking place around the year 2000 (*V.C. v. Slovakia*, *N.B. v. Slovakia* and *I.G. and Others v. Slovakia*) in front of the European Court of Human Rights (ECHR). 131

In all three cases, young Roma women signed consents for sterilization just before delivering their child through caesarean section under duress without being fully informed about the consequences of this intervention. This means they provided consent without being properly informed about the impact of the procedure on their health and body, without being offered possible alternatives, and without having enough time to consider any such decision. ECHR found violations of Roma female applicants' right to be free from degrading and inhuman treatment (Art. 3), and their right to private and family life (Art. 8). In the most recent judgment, *I.G. and Others v. Slovakia*, ECHR found violation of procedural guarantees of Article 3 of the *Convention for the Protection of Human Rights and Fundamental Freedoms*, emphasized the State's failure to promptly investigate allegations of torture, inhuman and degrading treatment or punishment, and ineffectiveness of civil proceedings.¹³² State officials continue to claim that all cases were derelictions of individual medical personnel.¹³³

NGOs have criticized the Government over and over for failing to put in place effective, prompt, and impartial investigative measures with regards to involuntary sterilization of Romani women. As the shadow report to Committee on the Elimination of all forms of Racial Discrimination (CERD) prepared by an alliance of NGOs notes, "despite three major victories of the victims at the European Court and despite recommendations from international bodies, the Government has not admitted its responsibility for the practice and has not compensated the victims at large. The Government keeps reducing the problem to occasional 'individual failures', however there has not been a single doctor who has been prosecuted for the practice." ¹³⁴

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¹³⁰ See also Body and Soul: Forced Sterilization and Other Assaults on Roma Reproductive Freedom in Slovakia (New York: The Center for Reproductive Rights and Centre for Civil and Human Rights or Poradňa, 2003) online: The Centre for Reproductive Rights, see at: www.crlp.org/pub_bo_slovakia.html#report

¹³¹ V.C. v. Slovakia, no. 18968/07, 8 November 2011, N.B. v. Slovakia, no. 29518/10, 12 June 2012, I.G. and Others v. Slovakia, no. 15966/04, 13 November 2012.

¹³² I.G. and others v. Slovakia, ibid. para 133.

See e.g. statement of the former Minister of Justice, Lucia Žitňanská at: www.webnoviny.sk/slovensko/sterilizacie-romiek-neboli-organizovan/439591-clanok.html?from=suggested_articles and of the Government Plenipotentiary for Romani Communities, Peter Pollák suggesting that "some doctors and hospitals failed, but one cannot say that Slovakia failed. It was not organized, it was not a policy of this country". Evening News, the Slovak Public Television (RTVS), November 14, 2012 at 19:20.

¹³⁴ Written Comments Concerning the Ninth and Tenth Periodic Reports of the Slovak Republic under the Convention on the Elimination of Racial Discrimination, jointly submitted by the Centre for Civil and

Nonetheless, litigations and advocacy of NGOs compelled the State to amend its legislation to stop performing involuntary sterilization as a life-saving procedure. 135 The human rights lawyer evaluates this legislation as satisfactory. More troubling remains its implementation into practice. She explains: "until health-care personnel believe they are the ones to decide over patient's life rather than the woman as a patient, the good legislation will not be working in practice. Informed consent means that I will offer you information about alternatives and risks, and that you will decide – not that the doctor will recommend you sterilization and then ask you to simply sign the form. That is the role of medical schools and health facilities to educate their health personnel. Until we will have the paternalistic approach in place, then I do not think we will make any progress. This is the case with patients in general, but it is more visible or perhaps detrimental with marginalized Romani women..." The women rights activist adds, "from my experience health personnel are making efforts to explain options to non-Romani patients that are more aware of their rights than in the case of poor Romani women with little formal education, offering up the excuse that Romani patients "would not understand this anyways."

Human Rights and People in Need (2013), January 2013, at 4. Available from http://poradna-prava.sk/wp-content/uploads/2013/03/PDF-236-KB1.pdf

¹³⁵ Health Care Act, *supra* note 64, in paragraph 40 section 2 requires written request and informed consent in case of sterilizations. This regulation of sterilization replaced an older directive of the Ministry of Health care that allowed for sterilizations on the grounds of health reasons. Directive no. 4582/1972 of the Ministry of Health Care of the Slovak Socialist Republic on performance of sterilizations.

5. ROMA SPECIFIC GOVERNMENTAL POLICIES

International intergovernmental bodies, as well as Slovak State agencies, have long acknowledged the need for specifically targeted State policies to address the issue of Roma exclusion in the health-care sphere.

The Council of Europe's Committee of Ministers, recalling numerous previous documents concerning the Roma's cause adopted in 2006 a comprehensive set of recommendations focused on Roma and Travellers' access to health care in Europe. 136 recommendations set out principles for preventing and combating discrimination in health care, as well as a common framework for health policies. In the section devoted to effective access, the Committee of Ministers endorses, among others, ensuring physical access to health-care services for Roma. Recommendations in the section on policy planning: mainstreaming of Roma needs into general policies as well as adoption of Roma specific policies. In addition, the Member States were asked to employ an intersectional approach linking health with other key areas such as employment, education, and housing. The recommendations also called on Member States to engage in a participatory approach in developing Roma related policies, to ensure sufficient budgeting and competent oversight, and to invest into research concerning this minority and health. These recommendations also stressed the importance of education of health-care personnel, as well as of campaigns aimed to raise awareness about Roma specific health issues among actual Roma populations. Particular attention is paid to health of children, and ensuring preventive (including vaccination, prenatal, and postnatal) care. The Committee of Ministers also underlined the need to pay attention to the health needs of underage females. The set of recommendations also touched upon reproductive and sexual health.

5.1. Policy Developments in Slovakia

The Government of Slovakia readily admits the need to adopt a focused approach to the Roma health situation, since the general legislative and policy framework patently does not suffice. That does not, however, mean that State policies are necessarily directly designed to help the marginalized Roma and provide certain assistance or benefits to this ethnic group. Instead, as early as in 1991, the Government, in its very post-socialist first strategy argued that State intervention should be justified on social grounds. 137

Generally, governmental strategies adopted since the social change in 1989 have paid least attention to the area of health. Policy documents from the early 1990 until 2000 tend to focus heavily on raising awareness among Romani children, youth, and adults with specific focus on reproductive and sexual health. In the first comprehensive strategy on addressing "problems of Romani national minority" of 1999, 138 health, received the least

¹³⁶ Recommendation Rec (2006) 10 of the Committee of Ministers to Member States on Better Access to Health Care for Roma and Travellers in Europe.

¹³⁷ Zásady vládnej politiky Slovenskej republiky k Rómom, adopted as an appendix to Government Resolution No. 153/1991, para C1.

¹³⁸ Stratégia Slovenskej republiky na riešenie problémov rómskej národnostnej menšiny a súbor opatrení na jej realizáciu – I. etapa, adopted as Government Resolution No. 821/1999.

attention with several rather vaguely drafted tasks aimed at awareness raising, tracking of infectious diseases, and increasing of hygienic control in Romani settlements. ¹³⁹ Nonetheless, a rather notable objective calls for priority establishment of home care and treatment agencies in Prešov, Banská Bystrica, and Košice regions. ¹⁴⁰ The second stage of this strategy, completed in 2000, comprises a more detailed set of commitments also covering the area of health care, ¹⁴¹ including a call for preventive check-ups (especially for Hepatitis A detection) among Romani children. Again, policymakers heavily focused on raising awareness related to hygiene, health life style, and reproductive health among Romani children and youth. For the first time, however, the Government also called on regional and district offices of State administration to monitor the quality of water sources in Romani settlements and to remedy deficiencies. For this task the Government allocated a budget of only 10,000 Slovak korunas (according to today's money it amounts to approximately USD 240).

A significant step in policy making in the area of health was made in 2002 when the OGPRC prepared a separate policy document focused on the health and environmental protection of people living in Romani settlements. The policy was titled "The Programme of Improvement of Environment, of Hygienic Conditions and of Prevention of Infectious Diseases among People Living in Romani Settlements," and despite the scarcity of available data on health status, access to drinking water, and environmental hazards in Roma settlements, it represented for the first time an attempt to draft evidence based policy. According to the data gathered form mayors and State institutions, in 2001 there were 420 Romani settlements, and 115,603 Roma in Slovakia. People living in Romani settlements disproportionately suffered from infectious diseases, dysenteries, scabies, and serious invasive meningococcal infections with high levels of mortality. Moreover, they were at an increased risk for chronic diseases such as asthma, lung and other cancer, metabolic disorders, poor nutrition, and alcoholic and tobacco addictions. The Government also recognized that Romani women's health were at high risk due to their high rates of child bearing at a relatively early age. 142

According to the programme, only 51 per cent of Romani settlements had access to drinking water from public pipelines, 6.3 per cent from regulated private wells, and 42.5 per cent from unsuitable resources. Only 23 per cent of the settlements had access to sanitary sewing. The programme furthermore observed unsuitable health standards and the existence of health hazards in proximity of settlements in particularly in Prešov, Košice and Banská Bystrica regions. The programme included measures in terms of awareness raising activities, improvement of hygiene and vaccination rates. The programme, however, also recognized the need to tackle unemployment and poor housing. The

¹³⁹ Section: Health Status, ibid.

¹⁴⁰ Task 3, ibid.

¹⁴¹ Rozpracovaná stratégia vlády SR na riešenie problémov rómskej národnostnej menšiny do súboru konkrétnych opatrení na rok 2000- II.etapa, adopted by Government Resolution No. 294/2000.

¹⁴² Program ozdravenia životného prostredia, zlepšenia hygienických podmienok a prevencie infekčných ochorení u obyvateľov žijúcich v rómskych osadách, adopted by Government Resolution No. 550/2002 at 3.

¹⁴³ Ibid. at 4–6.

¹⁴⁴ Ibid.

implementation of these measures was inadequate, if any, without any monitoring or evaluation.

Arguably, the Government of Slovakia has adopted one of the most comprehensive policy strategies as a response to a 2003 European Parliament request. It was called: Basic Theses in the Government Policy on Integration of Romani Communities. 145 The strategy, unlike previous rather poorly philosophically formulated policy documents, departed from a single normative framework of human rights. It relied on the so-called temporary equalizing measures (a Slovak term for affirmative action) as the central policy tool. The area of health specifically referred to the internationally recognized right to health as a basis for stipulating State commitments. The authors of the strategy called for, in addition to awareness raising activities, the establishment of a solid system of health mediators. Just such a programme, as described below, was indeed implemented using pre-accession PHARE funds. The strategy also sought procurement of mobile units to address the spatial barriers in accessing health care by marginalized Roma. Interestingly, in this policy document, for the first time in Slovakia's history, the Government committed itself to preparing and adopting a National Programme of Reproductive and Sexual Health that would take into consideration the specific vulnerable situation of Romani women. The strategy furthermore called for the elaboration of a comprehensive system of human rights education and training for health-care personnel. The MHC SR was charged to undertake intense training of health-care personnel in cultural competencies to improve communication with Romani patients. The authors of the strategy also focused on the drinking water access issue. During the interministerial commenting procedure, however, the original commitment requesting relevant ministries to "ensure access to drinking water" changed merely the mapping out of the situation on the ground and preparing a proposal of measures to ensure such basic need. 146 This mapping task was vested with the Ministry of Agriculture in cooperation with the Ministry of Environment (ME SR), which began work on it the same year.

On the basis of a list of Romani settlements provided by OGPRC, the ministries undertook mapping in 484 settlements. 147 The State's mapping revealed that out of 484 settlements, residents in 226 of them had access to drinking water from public pipelines, in 208 people used local wells with often questionable water quality, and that 50 settlements had no direct access to drinking water. 148 A significant portion of the document was devoted to very specific proposals for each locality, suggesting how to address the lack of drinking water. 149 A comprehensive solution of the problem with drinking water in these localities has not been adapted to date. The Basic Theses directive was nevertheless evaluated as partially fulfilled in 2004, as the call for action had been shifted to the regions to be implemented. 150

¹⁴⁵ Základné tézy koncepcie politiky vlády SR v integrácií rómskych komunít, adopted by Government Resolution No. 278/2003.

¹⁴⁶ Recollection of the author of this report that participated in the drafting of the strategy.

¹⁴⁷ Prehľad stavu zásobovania obyvateľstva pitnou vodou v marginalizovaných rómskych osídleniach s návrhom dočasných vyrovnávacích opatrení, adopted by Government Resolution No. 1117/2003 at 3.

¹⁴⁸ Ibid. at 3.

¹⁴⁹ See appendix 3, ibid.

¹⁵⁰ Vyhodnotenie Základných téz koncepcie politiky vlády SR v integrácií rómskych komunít za rok 2003, adopted by Government Resolution No. 397/2004 at 12.

Slovakia also joined a 2005–2015 international initiative called Decade of Roma Inclusion, which had as its stated goal the elimination of Roma discrimination and the reduction of the socioeconomic gap between Roma and the rest of the population in four priority areas (education, employment, health, and housing). Twelve European governments had pledged their support for the initiative, and the World Bank, the Open Society Institute, the UNDP, the Council of Europe, and the Council of Europe Development Bank were all its founding partners. ¹⁵¹ Each of the participating countries committed itself to prepare a national action plan that set out the goals and indicators in the four priority areas. Slovakia adopted its National Action Plan to Decade of Roma Inclusion ¹⁵² in 2005. In the area of health it set out four main goals:

- 1. Analysis of data on Roma health;
- 2. Improved access of marginalized Roma to health-care services, including improved awareness about health-care services;
- 3. Improved sexual and reproductive health;
- 4. Improved vaccination rates.

To achieve these objectives, the Government committed itself to three types of measures: 1) delivery of certain number of epidemiological studies on Romani health; 2) providing health mediators; and 3) leading preventive care (including vaccinations and sexual health) awareness campaigns.¹⁵³

Around year 2005, one could note some State efforts in providing sustainable funding for health mediators. This programme of only 30 health mediators, however, was first financed and coordinated by the MHC SR and later by the Public Health Authority (PHA) before being discontinued in 2011. 154

In 2008, the Government adopted another strategy, called *Mid Term Strategy of Development of Romani National Minority*. This strategy, rather vague in terms of particular commitments, includes a separate section called Health, Hygiene, Health Awareness, and Prevention. The plan recognizes the existing problems of inadequate hygiene, low health status, and drug addiction prevalent in Roma settlements. ¹⁵⁵ According to the government strategy, all these factors are the "result of insufficient awareness about reproductive health, lack of knowledge about health risks (nutrition, life style, smoking, drugs), insufficient information about hygienic and epidemiologic risks (drinking water, food), low awareness about the need to consult gynaecologists during

¹⁵¹ For more details please refer to the Decade of Roma Inclusion secretariat at: www.romadecade.org/

¹⁵² Národný akčný plán k dekáde začleňovania Rómov, adopted by Government Resolution No.28/2005.

¹⁵³ Ibid.

¹⁵⁴ According to the original plans, the programme was anticipated to last until 2015. Clearly there was not sufficient interest among concerned State institutions, in particularly the Ministry of Health Care to secure the funding. See *Program podpory zdravia znevýhodnených komunít na Slovensku 1. Etapa – Program podpory zdravia znevýhodnenej rómskej komunity na roky 2007-2008*, adopted by Government Resolution No. 680/2007 and *Program podpory zdravia znevýhodnených komunít na Slovensku na roky 2009-2015*, adopted by Government Resolution No. 609/2008.

¹⁵⁵ Strednodobá koncepcia rozvoja rómskej národnostnej menšiny v Slovenskej republike Solidarita – Integrita – Inklúzia 2008-2013, adopted by Government Resolution No. 183/2008 at 13.

pregnancy, insufficient knowledge about providing first aid, lacking network of community centres in localities with high concentrations of Roma, as well as a consequence of parents' failure to attend preventive care appointments, including for vaccinations of their children." ¹⁵⁶ The strategy then goes on to propose several measures written in vague terms such as "to decrease infectious diseases" or "to improve hygiene and prevention" or "to stop the increase of oncological diseases" or "to ensure access to drinking water," without specifying how, when, or by whom. A notable commitment seeks to "decrease birth rates" among the Roma. The entire under-budgeted strategy in fact contained only one firm commitment: to include health mediators into a catalogue of officially recognized occupations – something that has not yet been accomplished. ¹⁵⁷

Significantly more specific obligations were included in the Revised Action Plan, which also provided a number of operative commitments of the National Strategy of Roma Integration until 2012. The plan and its implementation will be further discussed in the section below.

5.2. Revised Action Plan of 2011 and NRIS of 2012

5.2.1. Preparation of the Revised Action Plan

After the parliamentary elections in 2010, OGPR (led by newly appointed plenipotentiary Mr Miroslav Pollak, and with the help and support of UNDP regional office in Bratislava and several others NGOs) initiated a revision of the national Decade of Roma Inclusion action plan. The explanatory report submitted to the Government explained that the 2005 plan lacks specifically designed tasks. Therefore, in April 2010 OGPRC created working groups on four priority areas, i.e. education, employment, health and housing, to prepare a set of policy measures that would form the new governmental strategy addressing exclusion of the Roma. Working groups included members of the State administration, municipalities, NGO's, Romani activist, and experts working in the area. Due to the reluctance of the Ministry of Education, Science, Research and Sport of the Slovak Republic (MESRaS SR), the working groups were put on hold until February 2011, with finalized material adopted by the Government in August 2011. 158 The 2012–2015 Revised Action Plan contains a set of tasks per priority area with relatively measurable indicators. Based on this author's observations, the Revised Action Plan was drafted in a participatory and inclusive manner. Nevertheless, the final wording of the tasks was greatly reduced by the comments of the ministries, in particularly in the area of education. 159

The Revised Action Plan focuses on five major goals:

- 1. To advance data collection and developing of legislative tools to improve monitoring of health of marginalized Roma;
- 2. To decrease spread of infectious diseases through increased vaccinations rates and improved hygiene;

¹⁵⁷ Ibid. at 15.

¹⁵⁶ Ibid. at 14.

¹⁵⁸ Explanatory report to the Revised Action Plan, *supra* note 1.

¹⁵⁹ I discuss implementation of the tasks in area of health in section below.

- 3. To improve access to drinking water;
- 4. To improve access to health-care services and awareness about health care among members of marginalized Romani communities;
- 5. To improve awareness about preventive care, sexual and reproductive health among Roma, and to enhance communication skills of health-care personnel.

The list of specific tasks to implement these five major goals¹⁶⁰ is more detailed than the previously adopted strategy and it recognizes, among other things, the need to address health data collection and access to health-care services. Preparatory works for the adoption of the Revised Action Plan indicate that there were several disputes between OGPRC (tasked with strategy creation), MHC SR, and PHA.¹⁶¹

The first disagreement concerned setting a system of ambulance units for providing health-care services in the settlements proposed by OGPRC. This proposal was withdrawn after objection by MHC SR. The MHC SR protested that they did not see any fiscal room for creating a secondary health-care system. Moreover, they viewed the financing of 72 additional ambulances as financially unviable. ¹⁶² A second, less surprising, argument arose about of the collection of ethnic data. PHA has agreed to include health data disaggregated according to Romani ethnicity in their annual report on the state of public health in Slovakia if the Institute provides them with such information for Collection of Health Care Data. However, it is not clear whether the latter would provide them with such information. Third, there has been shift of the responsibility for the health mediator's project from the MHC SR and the PHA to the OGPRC. ¹⁶³ Fourth, PHA refused to take responsibility for disinfestation, disinfections, and disinfections in Romani settlements. As explained by the PHA representative, PHA does not have sufficient financial resources for such activities. Consequently, the Government has assigned this task to municipalities, to be monitored by the regional PHA offices.

5.2.2. Preparation of the NRIS

The Revised Action Plan has become an operative part of NRIS, adopted in January 2013 as a response to the EC Communication "National Roma Integration Strategies: A first step in the implementation of the EU framework" (May 2012). In the section devoted to health care, the EC communication called on national governments to adopt their own strategies with the following goals in the area of health:

- Extend health and basic social security coverage and services (also via addressing registration with local authorities);
- Improve the access of Roma, alongside other vulnerable groups, to basic, emergency and specialized services;

¹⁶⁰ The entire section of the Action Plan is included in the appendix to this report.

¹⁶¹ Notes from the interministerial commenting procedure preceding the adoption of the Revised Action

 $^{^{162}}$ Please note that mobile health units should have been procured using pre-accession PHARE funds.

¹⁶³ Notes from the interministerial commenting procedure preceding the adoption of the Revised Action Plan.

- Launch awareness raising campaigns on regular medical checks, pre- and postnatal care, family planning and immunization;
- Ensure that preventive health measures reach out to Roma, in particular women and children;
- Improve living conditions with focus on segregated settlements.

In their recommendations on effective Roma integration measures in Member States, the Directorates General for Employment, Social Policy, Health and Consumer Affairs adopted at their Council Meeting on 9 and 10 December 2013 the following steps in respect to access to health care:

Take effective measures to ensure equal treatment of Roma in access to universally available health-care services on the basis of general eligibility criteria. This goal could be attained by means of measures such as:

- a. removing any barriers to access to the health-care system accessible for the general population;
- improving access to medical check-ups, prenatal and postnatal care and family planning, as well as sexual and reproductive health care, generally provided by national health-care services;
- improving access to free vaccination programmes targeting children and vaccination programmes targeting, in particular, groups most at risk and/or those living in marginalized and/or remote areas;
- d. promoting awareness of health and health-care issues.

Slovakia's NRIS was prepared in a rather short period of few weeks in late fall 2011, and adopted by the government in January 2012. As mentioned above, this newly adopted document provided a framework for Roma integration policies until 2020 with an action plan that ran to 2015. Moreover, the NRIS envisaged preparation of additional action plans covering areas of financial literacy, communication, and antidiscrimination. None of them have yet been completed.

In addition, unclear funding, deficiencies in coordination and participation of non-governmental actors in the monitoring and evaluation process all present obstacles to NRIS's implementation. ¹⁶⁴ The strategy is rather vague in terms of securing a clear source of funding for the operative commitments stemming from the Revised Action Plan. According to the strategy, the overall budget required for the implementation of the 2011 Revised Action Plan amounts to EUR 142 million. The Ministry of Health's budget for 2011–2015 was estimated at EUR 8,323 million. The Government envisions the use of State funds in combination with EU structural funds. Specifically, in the area of health, it merely notes a possibility of using the European Social Fund and the European Regional

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¹⁶⁴ Civil Society Report, supra note 70 c. 1, Updated Civil Society Monitoring Report on the implementation of the National Roma Integration Strategies in 2012 and 2013 in Slovakia (Budapest: Decade of Roma Inclusion Secretariat, 2013) at 9.

Development Fund to finance health mediators, awareness raising activities, as well as the construction of community centres which can cater to such intervention activities. 165

There is no available information about actual expenditures. However, interviewed State officials confirmed the lack of funding as one of the programme's deficiencies. ¹⁶⁶ As a State official in charge of the monitoring of these strategies at the OPRC stated, "it is a generally known truth that the strategy does not have any financial allocation." As a Ministry of Health employee explained, "the problem with these kinds of strategies concerning the Roma or human rights is that there is no allocated funding. Hence you can do only what you do in the regular course of your work".

The NRIS was consulted with civil society actors as well as with municipalities through a series of roundtables held across Slovakia. Among the participants were Romani NGOs and representatives of Romani civil society. However, interviewed Romani activists questioned if this process was in fact genuine participation. According to the interviewed Romani women rights activist, "it was a positive attempt to include us. This is certainly a welcome development in comparison to how strategies were prepared in the past. However, everything was already pre-determined. People could just express their ideas and maybe even objections. But objections have not been accepted and nobody even evaluated them. Moreover, in my view the Strategy does not contain any specific tasks and has no financial allocations. In this sense, the Strategy is not a qualified document, merely a formal attempt to "do something".... Moreover, generally setting up Roma policy at central level is difficult and more useful would be to focus on implementation and policy making at regional level to deliver a quality document in terms of clear and specific tasks backed up by an assigned budget."

Another Romani activist concurs: "I do not have a feeling and do not believe that this is what participation means. Roma strategy was already prepared when we saw it. It should have been the other way around. First people at local level should have met, discuss what the problems were and propose how to address them with the aid of a professional facilitator and experts to synthetize this local knowledge into a more general strategy. And this could be called participation. No one will tell you better than people who are in need about their needs. Not that you write something in Bratislava... although it should be appreciated that the strategy was presented before it was submitted to the government."

There is not any formal or informal mechanism for local or regional civic participation (be it Roma or non-Roma) in the monitoring and implementation of the NRIS. Monitoring reports of the tasks implemented should have been submitted by 15 February 2013, 168 yet the first evaluation report was presented only after a yearlong delay. According to information obtained from OGPRC, these delays were caused by failures of other ministries to respond to their requests for information on the implementation of the NRIS. In 2013, OGPRC gave EUR 10,000 from its grant scheme to two NGOs to prepare an

¹⁶⁵ NRIS, supra note 2 at 51.

¹⁶⁶ Civil Society Report, supra note 70 at 27–28.

¹⁶⁷ Ibid. at 23-24.

¹⁶⁸ NRIS, supra note 2.

external evaluation report on the implementation of the NRIS. ¹⁶⁹ However, it is noteworthy that OGPRC has specifically requested in its calls for evaluation of the NRIS that the authors of the evaluation "closely consult their proposal of activities with the office [i.e. OGPRC]." ¹⁷⁰ These reports have not yet been made public.

The civil society report most intensely criticized the fact that the Government elected in the early parliamentary elections in March 2012 showed little support for the NRIS, arguably because they were reluctant to acknowledge the document prepared by the previous administration. Instead, it introduced its own plan, the so-called "Roma Reform – the Right Way". The civil society report criticized this as being unduly repressive without offering opportunities for inclusion. They saw it in conflict with the Strategy, which explicitly rejects this approach. ¹⁷¹ Thus far, the Government has not been officially adopted Roma Reform as a strategic document and so it represents only a political statement, as explained by OGPRC's employees. Nevertheless, as part of Roma Reform, ¹⁷² parliament has adopted a New Act on Assistance in Material Need ¹⁷³ described in greater detail below. NGO's, the Slovak President, and the Public Defender of Rights criticized this piece of legislation as unconstitutional and in violation of international human right treaties have. ¹⁷⁴

The NRIS descriptive section on health recognizes that inequalities in health status between Roma and non-Roma populations can be measured both by both objective study and self-evaluation. ¹⁷⁵ NRIS acknowledges statistically significant differences in Roma versus non-Roma life expectancy (10 years less in Roma populations) and prenatal/infant mortality rates (3.3% higher among Roma).

See more details at: www.minv.sk/?zoznam-schvalenych-ziadosti-o-dotaciu-na-zaklade-na-zaklade-vyzvy-c-i-usvrk-2013

¹⁷⁰ See more details at: www.minv.sk/?vyzva_2013.

¹⁷¹ Ibid.at 22 and 32.

Please see e.g press release of Peter Pollák, GPRC, from 29 October 2013 at: www.minv.sk/?spravy_rk&sprava=urad-splnomocnenca-spusta-informacnu-kampan-o-zakone-o-pomoci-v-hmotnej-nudzi, see also public statements of the Minister of Interiours in a political discussion broadcasted by the Slovak Public Television, on 1 December 2013. Available from www.rtvs.sk/tv.programmes.detail/archive/28?date=01.12.2013

¹⁷³ Act No. 414/2013 Coll. on Assistance in Material Need 2013.

¹⁷⁴ The legislation was challenged by a group of NGOs, see "Pripomienka k návrhu novely zákona o pomoci v hmotnej núdzi – právny argument" 3/2013 Menšinová politika na Slovensku. Available from www.cvek.sk/uploaded/files/Mensinova%20politika%20na%20Slovensku%203_2013.pdf, at 2, the legislation was also challenged and vetoed by the President, see his press release from 15 November 2013. Available from www.prezident.sk/?rok-2013&news_id=18342 and by the Public Defender of Rights (ombudsperson) as unconstitutional in January 2014. The ombudspersons' legal challenge concurs with argumentation o NGOs is available from www.vop.gov.sk/podanie-na-ustavny-sud-zakono-pomoci-v-hmotnej-nudzi

¹⁷⁵ NRIS, *supra* note 2 at 34.

Among the main determinants of inferior health status, the authors included:

- 1. Low health and social awareness;
- 2. Low standards of personal hygiene;
- 3. Low standards of communal hygiene;
- 4. Low housing standards and exposure to environmental hazards (insufficient access to drinking water and infrastructure);
- 5. Poor nutrition;
- 6. Decreased actual access to health care due to the cost of transportation to health-care facilities.

According to the NRIS, Roma populations suffer from increased addictions to alcohol, tobacco and other substances. The strategy furthermore points out the increased incidence of congenital (genetically inherited) illnesses. The NRIS cites also cases of hepatitis, bacillary dysentery, scabies and lice as frequently occurring diseases disproportionately affecting segregated Roma.

Citing various NGO reports, the NRIS notes: "Roma may be discriminated against, for instance by being placed into segregated rooms... Slovakia has been since 2003 confronted with several cases of coercive sterilization of Romani women." Finally, the NRIS accepts that the State funded programme of 30 health mediators is insufficient.

NRIS focuses on following main goals:

- To support access to health care and to public health, including preventive health care and health awareness programme. To decrease differences in health status between the Roma and the majority population. This also includes improvement of hygiene in settlements and in urban ghettos, creation of a system of collecting solid waste (through environmental funds, separation, housing allowance) and ensuring mechanisms for regular disinfestation in segregated Romani communities in cooperation with self-government and members of MRCs;
- 2. To map out pollution and risks of living in localities of old environmental hazards and immediately address relocation of affected individuals of such localities;
- 3. To ensure accessibility and quality of drinking water;
- 4. To ensure accessibility of health care by addressing geographical and financial barriers, providing a programme of minimum dental care, improving communication between members of MRC and health-care personnel in providing;
- 5. To decrease infectious diseases rates by raising awareness and increasing vaccination shares, thus narrowing the gap between Roma and the majority population health;

¹⁷⁶ Interestingly during the preparation of NRIS, the ECHR already granted the first judgment in confirming coercive sterilization of a Romani woman in *V.C. vs. Slovakia*, see *supra* note 132.

6. To increase awareness about parenting, reproductive health, maternal health, child care; to devise a comprehensive non-biased outreach programme in sexual and reproductive rights for women and men from MRC and to include non-discriminatory, quality and free access to modern contraceptive methods and services for both women and men.

In terms of goal setting, NRIS identifies areas in need of intervention as specified by the 2011 EC communication on national strategies of Roma integration. The NRIS is somewhat more progressive than previous State strategies, especially in framing reproductive and sexual health rights. Still, it does not contain specific tasks how to fulfil objectives in this area. These are included in the Revised Action Plan of 2011, which became an operative part of the strategy. The report will discuss how these were in turn implemented.

5.3. Health Measures Addressing Roma Marginality implemented since 2011. Implementation of the Revised Action Plan

This section will evaluate the implementation of the Revised Action Plan, which forms the binding commitments of NRIS. The analysis draws on self-reporting of the ministries and relevant agencies, ¹⁷⁷ complemented by commentaries offered by the State administration, opinions expressed by non-governmental actors, and additional evaluation by this author.

5.3.1. Data Collection

One of the top priorities of the Revised Action Plan was to improve the State administration's ability to gather ethnically sensitive data. Indeed, as discussed in the first section of this report, data obtained through self-evaluation may be inaccurate. While demographic assessments of life expectance of Roma living in segregated environments reveal major ethnic disparities, self-evaluation offers what is likely an unrealistically positive picture. In this sense, clinical data in respect to health status are even more needed than in other sectors, for instance, in the education, housing, or employment. In these latter areas, information obtained via ad-hoc representative surveys may be sufficient to inform and guide polices.

The Revised Action Plan called for an innovative method of data collection based on ethnicity. It proposed linking the clinical data/medical files from health-care districts with the territorial map of Romani settlements prepared by the most recent Atlas of the Romani Communities. Subsequently, this information should be incorporated into the PHA periodic reports on the health of Slovakia's population.

This task has not yet been accomplished. According to the official explanation of the OGPRC, the release of Atlas's data results has been postponed until the first quarter of 2014, also delaying the consequent analysis by the National Centre for Collection of Health Data. A PHA official, in our interview confirmed that once their agency receives the ethnically disaggregated data on health, they would include it in the regular report. So far,

¹⁷⁷ This is included in the official evaluation of the implementation of the Revised Action Plan prepared by the OGPRC in February 2014 that has not been submitted to the government for approval yet.

such data has not been prepared. Yet, in advancing this method of measuring Roman health one should also pay attention to the data suggesting low percentage of Roma visiting health-care facilities due to financial hardship, spatial inaccessibility, or low health awareness.

5.3.2. Preventive Care with Specific Focus on tackling Infectious Diseases and increasing Vaccination Rates

According to the self-evaluation of the MHC SR, the State programme of health mediators should have realized the implementation of this preventive health task. The programme has, however, discontinued in 2011. Nevertheless, as of the measures implementing this task in 2012, MHC SR in partnership with the Roma Union Party distributed flyers in Romani language about the importance of vaccination in marginalized localities across the country. According to the official evaluation prepared by the MHC SR, this activity had no impact on vaccination rates. By contrast, significant impact on vaccination rates, tracking of infectious diseases, and improved access to preventive care was recorded for the Healthy Communities. The Healthy Communities programme replaced the previous programme of health mediators coordinated by PHA offices that terminated in 2011. The current programme of Healthy Communities is discussed in detail in the section below.

As rightly stressed by one of the interviewed Romani activists, there are major deficiencies and in fact no awareness raising activities concerning healthy lifestyle among Roma. She explains by drawing upon the experience of her family: "No one has taught them about healthy diet and healthy lifestyle. These are reasonable well-off people. High prevalence of cancer, diabetes, cardiovascular diseases... and you know all these are result of poor lifestyle choices and bad nutrition. This is the result of the tradition of consuming a lot of meat. Their meals are full of heavy and fat food. There is an enormous deficiency in preventive care. The only information that they receive is from cheap popular women's magazines. But this is not the case of the people living in poor settlements. They do not buy such press." The only initiative that addresses these barriers, albeit with in a limited scope, is the programme of healthy communities, discussed below.

There have been no focused activities to raise awareness of drug addiction and other socio-pathological issues, and to engage in harm reduction programmes targeting marginalized Romani locations.

5.3.3. Improved Hygiene, Disinfestation, Disinfection and Monitoring of Garbage Collection, Reduction of Environmental Risks

The Revised Action Plan anticipates regular monitoring of communal waste collection, monitoring of draining and cleaning of wastewater and of environmental hazards in marginalized Romani localities. According to OGPRC's self-evaluation, this task was partially fulfilled with the collection of data for the Atlas of Romani Communities (Collection of Atlas data was funded by the Ministry of Labour, Social Affairs and Family (MLSAaF SR) and implemented by UNDP). However, one time collection of Atlas data does not amount to regular monitoring. In terms of implementation of this task, MHC SR and/or PHA or the ME SR would be better suited to manage such oversight.

Furthermore, there is a need to designate a specific funding mechanism for disinfestation and animal control in Roma settlements, both being immediate health and security issues. Municipalities seem to have difficulties ensuring regular interventions on a need basis. According to an interviewed mayor, the removal of 30 dogs costs the municipality several thousand euros. This is simply something that municipalities cannot afford to do on a regular basis. Similar is the case with disinfestation. The last time PHA took disinfestation action was in 2009, when 100 Romani settlements were treated. The financing was, according to the information provided by the OGPRC, obtained through their grant scheme. The results, according to interview with a PHA representative, were questionable as some residents refused to allow their homes to be disinfested. Consequently the overall action did not deliver planned results. Such campaigns in the future would benefit from better overall cooperation and involvement of health mediators who could explain the importance and potential benefits (as well as possible risks) to settlement residents.

5.3.4. Access to Drinking Water

As explained in previous sections of the report, ensuring access to drinking water seems a task that Slovakia has major difficulty in accomplishing, in spite of a detailed monitoring framework and a set of decade old guiding principles. The Revised National Action plan calls again for mapping of accessibility to drinking water. This task, repeated again and again, has been accomplished with the completion of the Atlas.

Saliently, the task "support development" of resources of drinking water has been vested in the Revised Action Plan to the OGPRC. In its self-evaluation report, OGPRC claimed that the implementation of this task was supposed to be funded from the 2012 grant scheme. Due to administrative changes this has not yet been implemented, but in any case, OGPRC's grant scheme is insufficient to address such a vast problem. In the interviews, OGPRC agreed that this was given to them because no other ministry was willing to take on the responsibility. They realize that their competencies in this area are very limited.

At this stage, OGPRC has assumed a mostly coordinator role and has entered into negotiations with the ME SR and PHA to address deficiencies in access to drinking water in Romani settlements. OGPRC anticipates resources for the development of necessary infrastructure to be drawn from EU funds during the 2014–2020 programming period.

5.3.5. Improved Access to Basic, Emergency, and Specialized Health-Care Services

The only State measure that addresses the issue of access to health care is the Healthy Communities programme, discussed in detail in the section below. The Health Communities programme, which relies on work heath mediators, addresses problems associated with low health awareness among the Roma, urge them to attend preventive care treatment, including vaccinations, and to establish cooperation with the local general practitioners and paediatricians. Moreover, health mediators facilitate and help to improve access to emergency services and are specifically trained to communicate with the national First Aid Service. Also, health mediators accompany patients to specialized health services and book appointments, if needed. Regrettably, because of limited State funding, the Healthy Communities programme is unable to serve the entire Roma population in need of such assistance.

As suggested earlier in the report, the unaffordability of medical services is one of the chief health-care barriers for poor Roma. Regrettably, as of 1 January, 2014, the new legislation cancelled the rather modest EUR 2 support per person per month in material need to cover costs of health-care services. The Ministry of Labour, Social Affairs and Family of the Slovak Republic (MLSAaF SR) instead argued that the EUR 2 assistance was instituted in 2003 with the introduction of 20 Slovak crown co-pay (around EUR 0.80) per doctor's visit. When the out of pocket fee was later rescinded in 2013, the ministry has also dropped the EUR 2 assistance.¹⁷⁸

As indicated earlier, the new act expands the principle of so-called 'activation' in accessing basic support to those in need. This means that recipients of basic support are required to work 32 hours per month.¹⁷⁹ This prerequisite, however, does not apply to all people in material need – only those who are offered work. The municipalities select such arbitrarily. A notable aspect of the new policy is the calculation of financial penalty for missing job assignments. The amount decreases per capita as the number of individuals living in a single household increases. This means that the amount is EUR 61.60 in the case of single households, while it is only EUR 160.40 in the case of a two-parent household with up to four children.¹⁸⁰ Nevertheless, the penalty for not attending small communal services amounts to EUR 61.60 per person. This means the support in the case of a family of six is reduced by EUR 123.20, even though the financial assistance for one person under this scenario is EUR 26.70. Parliament passed this legislation over the president's veto in late November 2013. The actual implementation of this workfare scheme was delayed until June 2014.

While the legislation appears ethnically neutral, NGOs have argued that it can have an indirect impact on Roma. ¹⁸¹ Indeed, it is difficult to imagine that this legislation will be implemented on national scale given the size of people in material need and the scope of coordination that it requires. The MLSAaF SR proposed funding about 900 programme coordinator positions, yet that appears insufficient to manage a couple hundred thousand people who would qualify for the programme. Hence, as suggested by the Minister of the Interior, the primarily focus will likely be on Romani settlements. ¹⁸²

By contrast, in their comments on this report, MLSAaF SR argued that the legislation is based on a civic principle (i.e. being ethnically blind). According to their justification, material need assistance should be viewed only as a temporary additional support system of aid from the State. Its objective is to "activate" citizens in material need, and thus increase their responsibility to address their and their family's situation. The ministry has furthermore clarified that local labour offices will set up "activation" centres to assist municipalities in the implementation of the legislation, particularly in localities with a high share of people in need. Finally, the ministry, unlike NGOs, the president, and the

 $^{^{178}}$ Comments to this draft report submitted by the MLSAaF SR on 29 May 2015, under reference number $1187/2014\text{-M}_OSS,2360/2014$ at 2.

¹⁷⁹ Act on Assistance in Material Need, *supra* note 173.

¹⁸⁰ Ibid

¹⁸¹ See legal argument of NGOs and of Public Defender of Rights referred in *supra* note 174.

¹⁸² See his public presentation referred in *supra* note 172.

ombudsperson, believes that the legislation does not amount to forced labour prohibited by international law. ¹⁸³ The ministry argued that so called small communal services required in exchange for basic support in material need "constitute normal civic obligation of municipal members, for instance maintenance works, repair works, and in exceptional cases construction and infrastructural works to improve social conditions in the municipality (e.g. small school, doctor's office, and others)". ¹⁸⁴

The impact of the new legislation on Roma health can be manifold. First of all, there would be an obvious loss of minimum guaranteed income for the whole family and in particular the children. As I have explained earlier, reluctance of parents to engage in small municipal works affects also the amount of welfare support for children. In addition, according to information obtained from the Central Labour Office, the scope of the "small communal services" which the municipality can require of those in material needs is rather broad. For example, it could include work in infrastructure development, wood production, removal of illegal garbage sites, and others. The Government can get all services at almost no cost – only EUR 61.6 per person per month, or even less. According to NGOs, this kind of employment is outside the scope of minor communal works and implies forced labour. Finally, this type of work is not regulated by the Labour Code and is thus not protected by the code's standards and rights applicable to labour contracts. Being forced to engage in heavy manual labour under the threat of sanctions is harmful to fundamental aspects of people's dignity, self-respect, and health. Furthermore, safety standards have not been yet addressed in official communications.

5.3.6. Training of Health-Care Personnel

There have not been any specific efforts to commit to tasks associated with this objective. The civil society report notes marginal human rights courses and non-discrimination education of prospective medical and health-care personnel at universities and secondary schools for health personnel. Continuous and systematic effort to train existing medical personnel in this area is lacking. The interviewed human rights lawyer warns that this area of State intervention is greatly. The State, in her view, should take an active role and ensure life-long human rights education of health-care personnel.

5.3.7. Reproductive and Sexual Health

The only programme that addresses some aspects of preventive care related to reproductive and sexual health is Healthy Communities. It relies on the work of health mediators, and is discussed in greater detail below. Health mediators, typically in partnership with local schools, organize awareness raising activities targeted primarily at Romani teenagers.

Initially, the Revised Action Plan anticipated some additional funding for awareness raising activities relating to health to be secured through the OGPRC grant scheme.

¹⁸⁵ Information obtained from Ústredie práce, sociálnych vecí a rodiny on 18 February 2014.

¹⁸³ Comments of the MLSAaF SR, *supra* note 178 at 1–4.

¹⁸⁴ Ibid. at 5.

¹⁸⁶ See legal argument of NGOs referred in *supra* note 175.

¹⁸⁷ Civil Society Report, supra note 70 at 34.

However, funding was released neither in 2012, nor in 2013. OGPRC in its own evaluation argued that it could not be accomplished in 2012 because of administrative changes caused by the transfer of the office to the Ministry of Interior (MI SR).

The Romani women rights activist evaluated this area as suffering from great deficiencies. As far as prevention is concerned, she noted that the only currently active measure was for cervical cancer testing. There has been no palpable progress in ensuring access to oral contraception, for instance. According to her, over the last five years the State has mostly focused on restrictive rather than empowering policies.

Indeed, in the fall of 2013, parliament approved a new legislation prepared by the MLSAaF SR on State support for parents of new-borns. First of all, however, the current legislation somehow indirectly discriminates fourth, fifth and later children. In case of the first three children, State assistance amounts to EUR 829.86 per child. For the fourth, fifth, sixth and etc. children, the amount is only EUR 151.37. Sp by contrast, MLSAaF SR denies that the measure is implicitly discriminatory. The ministry defends this regulation as population control required by budgetary constraints. Sp

Furthermore, this support is not provided to mothers who have not regularly attended preventive gynaecologist check-ups at least once a month or mothers who have left the medical facility without the approval of the health-care provider. ¹⁹¹ The latter was already stipulated in the 2005 legislation. ¹⁹² MHC SR proposed further restrictions in late 2013, targeting the practice of Romani women leaving hospitals after giving birth. The currently debated amendment on health-care providers requires that hospitals promptly inform agencies for social and legal protection of children, as well as social parole officers, when mothers leave the hospital without permission.

MLSAaF SR argued that this regulation seeks to ensure the health and safety of the mother as well as her new-born child. The ministry in addition notes "the stay of a mother with her newly born baby in the health-care facility expresses generally accepted, common, and natural behaviour of the mother after giving birth." In addition, MLSAaF SR also noted that the health-care providers are vested with an opportunity to release mothers and their new-borns after giving birth. 194

By contrast, a group of women and reproductive health rights advocates objected to this legislation by suggesting that maternity wards and hospitals are not prisons. NGOs argued that there is no law setting precisely the period during which women need to stay in the hospital after giving birth. In their view, the doctors cannot mandate this. They opposed

¹⁸⁸ Act No. 383/2013 Coll. on Support When Giving Birth to a Child or Giving Birth to Two or More Children Simultaneously, para 4 sec 1a.

¹⁸⁹ Ibid. para 4 sec 1 b.

¹⁹⁰ Comments of the MLSAaF SR, *supra* note 179 at 6.

¹⁹¹ Ibid. para 3 sec 4 a and b.

¹⁹² Act no 471/2005 Coll amending Act No235/1998 Coll on Child Allowance When Giving Birth etc.

¹⁹³ Comments of the MLSAaF SR, *supra* note 179 at 6.

¹⁹⁴ Ibid. at 6.

the legislation as deeply disrespectful of the autonomy of women.¹⁹⁵ MHC SR has not accepted their objections. The interviewed human rights lawyer does not believe this legislative change addresses the causes of this Romani custom, but rather only penalizes the consequences.¹⁹⁶

As far as the informed consent is concerned, in 2013 MHC SR introduced a new legally binding regulation providing details on the written instruction given by medical personnel before obtaining informed consent for health-care procedures. The regulation, which went into effect April 2014, includes a template of consent in national minorities' languages, including Romani. 197

While the NGOs welcomed this proposal, they considered it "insufficient to secure proper implementation and prevent illegal sterilizations in the future." ¹⁹⁸ NGOs note "it is necessary that the medical personnel understands the concept of informed consent; that is to understand it is not a mere signature on a form containing lengthy wordings (even in Roma language), but, most of all, interactive communication between the physician and the patient reflecting the individual circumstances of each case. Health-care personnel have to also take into consideration the cognitive and language abilities of the particular patient and to adequately explain the nature of the medical intervention to them. Medical personnel shall be trained in this regard taking into account the human rights background of this institute and also the possible specifics of marginalized groups and ethnic minorities." ¹⁹⁹

Adoption of the National Programme of Reproductive and Sexual Health has been delayed until 30 October 2015. It is unlikely that this programme will be passed, as there has been strong opposition by the Roman Catholic Church since 2003.

¹⁹⁵ Press released of women rights NGOs entitled "Hospitals are not Prisons" from 27 January 2014. Available from http://poradna-prava.sk/wp-content/uploads/2014/01/PDF-110-KB.pdf

¹⁹⁶ Please see on this practice in more detail also s.3.6, above.

¹⁹⁷ Referred in self-report of the OGPRC.

¹⁹⁸ Shadow report submitted by a coalition of NGOs. Available from http://poradna-prava.sk/wp-content/uploads/2013/03/PDF-236-KB1.pdf at15.

¹⁹⁹ Ibid.

6. EXAMPLE OF GOOD PRACTICE – HEALTH MEDIATORS

6.1. Background Developments – KARI and PHARE Programmes

The health mediator programme is arguably the only initiative in Slovakia specifically designed to improve marginalized Roma's health-care services access. The programme began as an NGO initiative in the early 2000s. The Regional Association of Romani Initiatives (Krajská asociácia rómskych iniciatív (KARI)) started in 2002 their programme entitled "Paediatrician's Assistant." As the organization's director, Nataša Slobodníková recalls, "the programme was somewhat inspired by the calls of paediatricians to address low preventive services attendance among poor Roma."

Slobodníková, drawing on her previous experience as advisor of the chairman of Banská Bystrica region, has developed the programme's methodology and involved relevant stakeholders, i.e. marginalized Roma, the doctors, mayors, and the State administration. With financial support from the Labour Office, her NGO first trained and later employed twenty Romani women at the Secondary Health-Care School in Lučenec. The programme was launched in partnership with 10 paediatricians targeting 10 localities in Banská Bystrica Region.

The programme focused on preventive health care, vaccinations, awareness rising, and more general aspects of access to health-care providers. Slobodniková recalls "the programme targeted barriers that Roma were facing in accessing health care 10 years ago. Assistants often accompanied patients to see their doctor. We could notice palpable changes in attitudes of health-care providers. Doctors changed their views and recognized sincere efforts to cooperate on the part of their Romani patients." The programme ran from 2002 until 2004 with a yearly budget of 2,300,000 Slovak crowns (EUR 77,000). Programme expenditures included salaries for 20 health assistants and the project coordination.

With an ambition to institutionalize the programme, KARI then offered its know-how to MHC in order to secure its financial stability. The ministry piloted the programme using pre-accession PHARE funds, ²⁰⁰ and called it "Improvement of Access of Roma Minority to Health Care in the Slovak Republic" (hereinafter "the PHARE programme").

The ministerial programme was also conceived as a measure fulfilling State commitments towards the implementation of the government strategy called Basic Theses in the Integration of Romani Communities, adopted in 2003 and mentioned earlier in this report.

The PHARE programme lasted from September 2005 until 31 December 2006. It included the following components:

1. recruitment, training, and temporary employment of health mediators in selected micro regions;

PHARE program 2003-0040995-01-06. Available from www.health.gov.sk/Clanok?projekt-phare-c-2003-004-995-01-06-zlepsenie-pristupu-romov-k-zdravotnej-starostlivosti-b-ukonceny-b

- 2. training of key stakeholders including social field workers, local authorities, and local doctors;
- 3. procurement of training tools;
- 4. procurement of health-care equipment;
- 5. procurement of mobile health units:
- 6. renovation of health-care centres.

The biggest share (EUR 840,000) of the programme's budget was assigned to the health mediation component, and the actual mediation implementation was subcontracted to a private consulting company called EuroPlus Management and Consulting s.r.o.

The programme targeted 59 municipalities in 17 micro regions, and run by two coordinators, and 40 health mediators. Mediators worked on a daily basis with local doctors in areas of preventive care, vaccinations and general access to health-care issues. In addition, health mediators were expected to establish partnerships with local authorities, including municipalities, NGOs, and schools. The assistants monitored the health situation in their areas, undertook awareness raising activities with respect to healthy lifestyle choices, hygiene, prevention and drug harm reduction, maternal health, parenting, and others.²⁰¹

According to the final report of the programme, health mediators had created a functional and well-coordinated system helping marginalized Roma to access preventive and basic health-care services, as well as improved early diagnostics across all age groups. ²⁰² On the other hand, the final report prepared by Michal Obuch found unreasonable administrative workload, delays in cash flow, and time consuming decision-making processes as the main downfalls in the project implementation. Furthermore, health mediators had become frustrated by the uncertainty of the programme's continuation. This also meant a decrease in mediators' motivation to invest time and energy in continuing training and education. Since health mediators did not have any alternates, days off or holidays meant interruption of service coverage. Other risks factors included physical attacks caused by alcohol consumption of clients targeting health mediators of clients, in particular during welfare benefit paydays, risks of infections and of dog bites. The report also noted that the target group shared a degree of scepticism about yet another project declaring to help Roma people. ²⁰³

The final report included the following recommendations on how to improve the positive impact of the programme:

- 1. to increase the numbers of mediators to at least one health mediator per settlement;
- 2. to set up coherent methodological standards of health mediators training;

²⁰¹ Information at web site of MZ. See at: www.health.gov.sk/Clanok?projekt-phare-c-2003-004-995-01-06-zlepsenie-pristupu-romov-k-zdravotnej-starostlivosti-b-ukonceny-b

Michal Obuch, Zabezpečenie lepšieho prístupu rómskej menšiny k zdravotnej starostlivosti v SR prostredníctvom vyškolených terénnych zdravotných asistentov (časť 1 – Obstarávanie a výkon práce systému terénnych zdravotných asistentov pre stanovené mikroregióny) – Záverečná správa, 2007 at 107, available through the web site of the Ministry of Health care at: www.health.gov.sk/Clanok?projekt-phare-c-2003-004-995-01-06-zlepsenie-pristupu-romov-k-zdravotnej-starostlivosti-b-ukonceny-b

²⁰³ Ibid. at 104.

- 3. to institutionalize the scheme and ensure sustainable funding;
- 4. to increase the educational requirements for health mediators to secondary education in any area. However, in weighting the qualifications and ethnicity of health mediators, the priority should be given to the latter one;
- 5. to ensure proper working conditions that include space for their trainings, contacts with target group members, or preparation of project reports.²⁰⁴

Slobodníková questioned the efficiency of this programme. According to her, the allocated budget should have been used to employ at least 250 assistants. It was also unclear, she noted, what had happened with the mobile units, i.e. ambulances that had been purchased.

The programme continued with 30 mediators in 2007–2008, first using the State budget allocated to MHC, and later shifting to PHA. The civil society report notes that public officials shared their concerns about this switch as regional offices were forced to make their employees redundant and hire Romani health mediators instead. In 2009 and 2010, programme costs amounted to EUR 300,380 per year. According to evaluations from 2011, during the 2007–2008 period, the 30 mediators covered 117 settlements, while in 2009–2010, the number of settlements covered increased to 122. ²⁰⁵ The overall budget allocated for the project during this period was EUR 865,895, and the regions receiving the most attention were those with the highest share of MRCs, i.e. Prešov, Košice, and Banská Bystrica. ²⁰⁶

The programme's objectives were to facilitate communication between marginalized Roma and health-care personnel, increase awareness about health and cooperation with schools, social field workers, municipalities, and health insurance companies. ²⁰⁷ Health mediators were hired by local public health offices on the basis of a contract of mandate, instead of a regular employment contract. Health mediators were expected to work four days a week in the field and one day in the office to evaluate and plan activities for the upcoming week, and to prepare their activity reports on a monthly basis. ²⁰⁸ Qualification requirements for health mediators included completed elementary education and knowledge of Slovak and Romani (at a level allowing effective communication). Completed secondary education, knowledge of Hungarian, or participation in previous State or NGO funded health mediation initiatives were considered to be an advantage. Membership in a Romani community was not a requirement, but rather an advantage along with other skills such as accountability, motivation, or possession of good communication skills. The health mediation coordinators were required to have completed secondary education. ²⁰⁹

²⁰⁴ Ibid. at 104–105.

²⁰⁵ Informatívna správa o efektívnosti výsledkov získaných plnením 2. etapy Programu podpory zdravia znevýhodnených komunít na Slovensku na roky 2009–2015, Úrad verejného zdravotníctva Slovenskej republiky, Bratislava, 31.marca 2011 at 4.

²⁰⁶ Civil Society Report, supra note 70 at 68–69.

²⁰⁷ Informatívna správa, supra note 205 at 4.

²⁰⁸ Ibid.

²⁰⁹ Ibid. at 6–7.

Health awareness education was focused on personal hygiene, prevention of infectious diseases, epidemics and health incidents, reproductive and sexual health, food safety and nutrition, environment, health care, and child caring. According to the internal evaluation report, the programme has contributed to the increase of vaccination rates and preventive check-ups, improved communication between marginalized Roma and health-care providers, improved coverage of marginalized Roma with valid health insurance cards, and improved health awareness of the targeted communities. ²¹⁰

Table 7: The Programme of Health Support of Disadvantaged Communities in Slovakia in 2007–2010

| | Activities initiated by health | Number of Targeted Persons/Clients | | | |
|----|--|------------------------------------|--------|--------|--------|
| | mediators | 2007 | 2008 | 2009 | 2010 |
| 1. | Preventive check-ups | 4,399 | 4,018 | 4,971 | 4,884 |
| 2. | Vaccinations | 6,855 | 9,840 | 10,161 | 10,743 |
| 3. | Blood works | 1,200 | 1,137 | 1,668 | 1,798 |
| 4. | Paediatric consultations | 2,625 | 2,571 | 2,607 | 3,534 |
| 5. | Medical treatment | 1,556 | 1,213 | 1,585 | 1,612 |
| 6. | Check-ups | 1,515 | 1,193 | 1,244 | 1,451 |
| 7. | Obtaining health insurance cards | 2,001 | 1,269 | 888 | 1,498 |
| 8. | Monitoring of environment, health and life style | 3,947 | 1,717 | 2,074 | 3,690 |
| 9. | Health education | 26,882 | 38,687 | 39,707 | 39,672 |

Source: Informatívna správa o efektívnosti výsledkov získaných plnením 2. etapy Programu podpory zdravia znevýhodnených komunít na Slovensku na roky 2009-2015, Úrad verejného zdravotníctva Slovenskej republiky, 31 March 2011 at 15.

The internal evaluation report assessed the following as the programme's strong points: improved ability to diagnose health problems and devise suitable health interventions, improved behaviour of Roma in health-care facilities, improved communication between the majority and the minority. In addition, the programme contributed towards more efficient communication between the Romani patients and health-care personnel. At the same time, the report stresses that with only 30 health mediators, it is unreasonable to expect major or sudden changes in health awareness levels or general health conditions of the community in focus. This is a long-term process that does not depend solely on the health-care sector performance.²¹¹

Among the weak points of the programme, the report notes the low level of interest among marginalized Roma. The report cites that some Romani families refused to have their children vaccinated. Health mediator's access to communities is curtailed by wandering dogs and increased Roma alcohol consumption after welfare distribution.

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²¹⁰ Ibid. at 14.

²¹¹ Ibid. at 17–18.

Furthermore, fluctuation in the number of health mediators had a negative impact on the programme, causing difficulties in terms of training and establishing contacts with the target community. According to the report, one of the most serious difficulties was the programme financing. In 2007–2008, its funding was ensured by the budgetary chapter of the MHC SR. However, in 2009–2010, PHA was asked to allocate a portion of its budget for the programme, but since the overall PHA budget had not increased, this meant a decrease in available funds and the need to lay off core employees. Nevertheless, the report concludes that the programme made a positive contribution to Roma health.²¹²

The civil society report notes also the ongoing dispute about what exactly constitutes proper health mediator qualifications. According to the prevalent view, shared by State officials, health mediators should be included in the official catalogue of occupations to secure their sustainable employment through regular employment contracts. Thus, the State has temporarily employed health mediators using contracts of mandate renewed on an annual basis. The programme was delayed each year due to insecure funding. This has probably also caused the relatively high work fluctuation of health mediators. Moreover, there appeared to be insufficiencies in providing systemic training. Finally, the employment of 30 health mediators, initially conceived as temporary, remained permanent one until the termination of the project in 2011. Yet, both the State administration as well as NGO actors agreed that 30 health mediators is an insufficient number given the size of marginalized Romani population. 213

In 2011–2012, the programme was put on hold. According to available sources, relevant State agencies, i.e. the MHC SR and the Government Office, have been shirking their responsibilities in securing funding or requesting funds from the State budget.²¹⁴

6.2. Healthy Communities Programme

Parallel to these developments, another NGO, the Association for Culture, Education, and Communication (ACEC) – founded in 1999 to work primarily in the cultural domain – began developing their own health mediation programme. The NGO's president Ľubomíra Franz Slušná recalls: "I was simply astonished by the health situation in Romani settlements." She was determined to develop a programme that would help Roma to help themselves in improving their health with the help of health mediators. The programme was called Healthy Communities and is to this day the largest State-funded NGO activity and indeed the only palpable initiative towards fulfilling NRIS objectives in the area of health for the period 2013–2014.

The programme started its pilot phase in 2003 in 11 localities with the help of private funding. From 2007 until 2009, the programme expanded to 68 settlements, while targeting 45,000 people. In 2010, the programme downscaled to 30 settlements. Since 2011, it has expanded to 33 localities with 42 health mediators and three coordinators. Its main activity focused on increasing health literacy, improving Roma health, and increasing access to health care. ACEC developed its own accredited training programmes

²¹² Ibid. at 18–19.

²¹³ Civil Society Report, supra note 70 at 68–69.As reproduced in ibid.

²¹⁴ Ibid.

certified by the Ministry of Education. In 2004, the training programme was called a Community Worker – development of knowledge and skills in work with Romani community. In 2007, the programme was renamed to Assistant of Health Awareness in Romani Communities.

Healthy Communities relies on the work of health mediators recruited from marginalized Roma communities, and focuses heavily on empowering people living in marginalized settlements. It is structured according to the particular needs on the ground. As Franz Slušná explains, "simply we have to accept that in some localities people do not have access to drinking water, never mind a regular bathroom. We have to teach mothers how to take care of their baby and to ensure their safety even under these conditions." Strongly encouraged to build relationships with key actors on the ground, health mediators have been continuously trained in health literacy and communication skills to successfully work with their target group and local public administrations. Franz Slušná, who is an experienced coacher of business entrepreneurs, kept telling health mediators to "never give up, they [i.e. municipalities' willingness to cooperate] will give its way. If the mayor said he would call, wait one or two days. If nothing happens, politely remind him your request and call back."

The only mediator qualification was compulsory school attendance. Hence, even attendance of special school was sufficient. A more relevant criterion for recruitment as a health mediator, along with membership in the target group was the level of personal commitment. As the coordinator of the current expanded programme Zuzana Pálošová explains, "we recruit people that take their work as their personal mission, something that empowers them and gives meaning to their lives". ACEC health mediators were technically volunteers whose telephone and other costs (totalling approximately EUR 70 a month) were reimbursed. They were required to work eight hours a week, however according to an internal ACEC evaluation, in practice they work on average of 8.5 hours a day. Their core activities include: regular visits to people's households, guidance of patients to health-care providers, assistance and aid for mothers with their first born child, regular visits to patients suffering from chronic illness, health-care awareness activities, providing information about available help, and providing first aid.

In quantitative terms, according to an internal ACEC survey, ten health mediators working in ten localities during a period of five months in 2012 delivered the following services:

- > 7977 contacts with clients;
- > 119 hospital visits;
- > 512 consultations with doctors;
- > 739 specific help for families;
- 289 health awareness activities;
- > 330 communications to solve specific health problem with health personnel.

According to the statistical data of one of the health insurance companies, the programme had significant impact on the vaccination care and preventive check-ups. 215

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²¹⁵ Information obtained from ACEC in March 2014.

ACEC and its determined leader Ms Franz Slušná sought out several strategies how to expand and institutionalize the programme in the course of the last ten years. Clearly, Slovakia would need 450 to 500 coordinators to address the needs of people living in excluded Romani localities. Another interviewed Romani activist also concurred, "there has to be a minimum of one health mediator per locality. But in cases of large settlements like Jarovnice (with several thousand people), one mediator is far from sufficient. She or he can provide services to 20 families? What will happen with the rest?"

As part of their advocacy strategy, ACEC first set up a platform to support the health of disadvantaged groups with the closely related aim of improving the health of people living in Romani settlements. The platform brought together key stakeholders – including ACEC, Association of health mediators, GlaxoSmithKline, the Office of WHO in Slovakia, the First Aid Service, Slovak Society of General Practitioners, and Union Health Insurance Company. The platform cooperates with other actors: The Ministry of Finances of the Slovak Republic, The Ministry of Labour, Social Affairs and Employment, MHC, PHA, OGPRC, and Open Society Foundation. The central goal of the programme has been the development of a systematic solution in times when State institutions are failing in reducing barriers in accessing health care for marginalized Roma. The platform has the ambition to prepare a national programme that would ensure financing of the entire programme with EU funds.

The platform, engaging a wide variety of stakeholders, is led by a skilled medical practitioner in the area of Roma health, Dr Marko. The programme, by holding regular meetings and promoting the initiative's expansion, eventually convinced the authorities to fund, so far, the most extensive State-funded project. The platform, with support and aid from the OGPRC, the MI SR, the MLSAAF SR, and the Ministry of Finances (MF SR) sought financing for the period October 2013—June 2014 for a total budget of EUR 1,086,909. The funding came from the budget of the Ministry of Finance via the Office of the Government Plenipotentiary for Romani Communities. This budget allowed employing a total of 121 persons — 105 assistants, 12 coordinators, one chief coordinator, an executive secretary, and an accountant. According to the internal progress report of ACEC, the programme targets 108 marginalized Roma localities with direct positive impact on 110,097 people living therein. The programme has an indirect positive impact on 426,909 persons living in the majority population.

The programme was later extended to 30 September 2014. Additional financing of approximately EUR 400,000 was released from the MF SR budgetary chapter. The additional funding allowed the number of health assistants to increase to their current number of 190. After lengthy negotiations and a period of uncertainty in terms of funding, finally MHC SR in partnership with the programme established a non-profit organization called Healthy Communities, n.o. Health Communities has applied for funding from the operational programme Employment and Social Inclusion administered by the MLSaF SR using remaining resources from the programming period 2007–2013. The funding became available on 1 October 2014 and will last until 31 December 2015. The EUR 3,000,000

budget allocated for this period allows for an increase of the number of health-care assistants to 298. ²¹⁶

The programme debuted in June 2013 with three recruitment rounds and an initial training session for health mediators. Another series of six training rounds took place until December 2013. The training is based on two programmes – Assistant of Health Awareness (88 classroom hours) and Community Worker (192 classroom hours).

Health assistants (i.e. health mediators) training is centred on several themes:

1. The Role of Health Mediators

Training provides participants with general information and facts about the social and health situation of Roma living in settlements. This course also brings together theory and practice to demonstrate how health mediators can improve health status in these localities by focusing on preventive care and health-care assistance. Participants develop their skills to analyse their clients' needs and advance practical and doable solutions.

2. Basic Skills in Working with Roma Community

Training focuses on developing skills to successfully communicate with the target group, as well as health-care providers, municipal self-governance representatives, and other stakeholders.

3. Basics in Human Biology

This course teaches basic anatomy and physiology of the human body. In addition, it provides an overview of common diseases and methods of health prevention.

4. Basics of Disease Epidemiology with Specific Focus on Infectious Diseases

This course looks at the conditions under which infectious diseases spread, how to prevent their spreading, how to recognize symptoms, and how to ensure necessary hygiene.

5. Specialized Social Health-care Counselling

This course equips participants with capacities necessary for successful communication with health-care providers. Students learn how the health-care system functions, how to seek specialized medical services, how to assist in the application for health insurance cards and similarly.

6. Pregnancy and Early Childhood Care

Course participants learn about how to provide assistance and counselling to pregnant women and mothers. The course also covers medical, legal, and financial aspects related to pregnancy and parental support.

²¹⁶ Information provided by ACEC on 5 November 2014.

In addition, course participants learn how to provide first aid. The National Emergency Service delivers this training.

Source: ACEC.

The first training of health mediators was organized in June 2013. Course participants learned about patients' rights and developed their own code of ethics, endorsing respect for equal dignity of all people regardless of their circumstances as its key value. As the president of ACEC, Franz Slušná kept repeating at one of the trainings, "never shy away from anyone or be arrogant ... no matter how poor or unclean the person is." During the project's first phase, ACEC informed and sought to establish partnership with all relevant stakeholders, including the regional public health office authorities and the National Emergency Service. As Franz Slušná explains, "it is absolutely critical that the emergency service personnel know when the health assistant is calling to seek consultations."

Health mediators began their work in the field on 7 October 2013. Among their first tasks was to introduce themselves and the programme to all stakeholders, i.e. Romani families, doctors, mayors, social field workers, and school principals. Coordinator Pálošová recalls shortly after these introductory sessions, "they quickly become loaded with work. Doctors gave mediators lists of children to attend vaccination and preventive check-ups... mediators have built their reputation amongst the Roma they have been working with, as soon as they successfully solve some health issue." One of the interviewed health mediators recalled how he had organized, in partnership with the local general practitioner, a major medical screening for infectious diseases in the locality where he works. He noted that the knowledge of Romani language and of the environment was absolutely critical for the successful completion of this task.

As mentioned earlier, the qualification requirement for health mediators is set rather low: completion of compulsory education, even at special schools suffices. According to ACEC experience, the lack of higher education is an obstacle that can be overcome through systematic training. It is imperative that people are committed and come from the marginalized locality. Moreover, as project coordinator Pálošová stressed, it was absolutely vital that health mediators have a clear understanding of medical treatments. Pálošová noted, "only if they understood why, will they be able to convince their clients to do something and change some of their practices".

These observations confirm the findings of the PHARE funded programme mentioned earlier in this section. While the author of the final PHARE programme report concluded that health mediators should have higher education, Obuch also stressed belonging to the targeted group (being of Romani origin). At this point it is worth recalling the Slovak experience with the Social Field Work programme funded by the European Social Fund, where the admission bar was set so high (completed university education) that in reality the majority of potential Roma applicants were automatically disqualified.²¹⁷

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²¹⁷ Obuch, *supra* note 202.

Contrary to the findings of the PHARE evaluation report, Pálošová suggested that having an administrative space for their work may not bring desirable results. Health mediators, she explains, "are expected to work permanently in the field. This includes visiting Roma families, doctor's offices, municipal offices, etc. They have a lunch break and their paperwork and reporting requirements are kept to minimum. We believe that if they had some separate room and/or administrative space, it is likely that they would stay there and would not do the field work that is key for the programme. Indeed, this has been one of the downfalls of the programme of social field workers."

Health mediators keep in close contact with their assigned coordinator, as well as with the central coordination unit. Most frequently, mediators have listed vaccinations and preventive check-ups among their activities. Mediators have also accompanied patients to the doctor's office. Often they have helped to make an appointment with a specialist in regional or distant cities, as well as helping mothers to remove lice using a variety of strategies. Health assistants have also organized sexual education classes at local schools. While waiting for an ambulance with the expectant mother, a couple of health mediators helped the pregnant women to give birth following telephone instructions from the emergency service.

According to the ACEC progress report based on weekly reports from the assistants for the first three months of programme implementation, mediators had undertaken the following activities:

Invitations to preventive check-ups (A), Compulsory vaccinations (B), Cooperation with doctors (C), Health education and health awareness activities (D), others (E).

Within the group A are following sub-sections: Invitation to preventive check-ups of children (A1) and Invitation to preventive check-ups of adults (A2).

Within section B there are two sub-sections: Invitation to compulsory vaccinations (B1) and participation in vaccinations with their clients (B2).

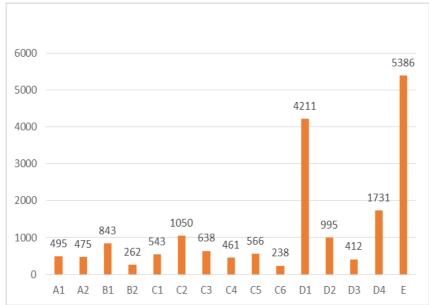
Within the section *C*, there are more sub-sections:

Telephone communication (C1); Personal visits (C2); Paediatrician (C3); General practitioner (C4); Specialist (C5); Hospital (C6).

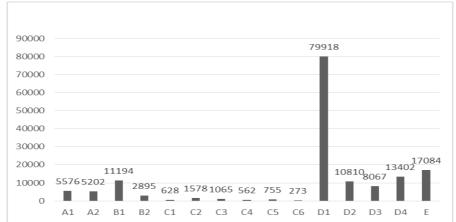
Group D includes the following interventions: Family (D1), Youth (D2), School (D3), others (D4). Group D includes further interventions such as high blood measurements, assistance with providing medications, checks of newborns, calling emergency services, administration, work with employees in non-health-care facilities, such as schools or municipalities, trainings, etc. These codes are used in the following tables and graphs.

Group E does not have any subsections.

Graph 1: Number of interventions



Graph 2: Number of clients



Source: ACEC, March 2014 (First table refers to number of interventions and the second to the number of clients served by the programme).

In the first three months of the project, health mediators helped to address several serious infectious diseases, including Hepatitis, Tuberculosis, and scabies. Health mediators have also initiated outside their workings scope brigades for cleaning the settlements and their surroundings and/or the sources of drinking water.

An interviewed mayor in one of the villages targeted by the programme generally welcomed the programme, stressing their important role in "prevention of risks associated with spreading infectious diseases among the majority population." He is the mayor of a rather large village in eastern Slovakia. The Romani settlement situated on a segregated site of the village is home to approximately 1,600 people. The settlement consists of dwellings of variety of standards. They range from poor wooden shacks to concrete houses, an older flat of houses to rather ostentatious houses with spacious gardens allegedly owned by local usurers. Only a few of the houses have proper legal titles to their homes (i.e. are built with regular building permit), and thus access to drinking water. The vast majority of people rely on one source of water – a water source situated

in front of the settlement. People walk all day long with buckets of water, which they carry to their homes. The health mediator in this locality worked in close partnership with a doctor who is directly involved with the ACEC programme in order to screen residents for a variety of infectious diseases, tracking people at risk of infection from an individual who had tested positive for TBC, and ensuring that his clients attend preventive check-ups and vaccinations dates.

A paediatrician who treated Roma patients from a nearby segregated settlement recalls: "It was like Uganda, I had to deal with diseases that we have not had in the general population for thirty or forty years. For instance, rachitis caused by lack of Vitamin D in children." She noted that when she started working in that locality, no one from the settlement would come to her office. "Maybe it was the distance, but also perhaps other issues. Parents simply would not bring their children to my office." The doctor set up a field office in the village to provide services directly twice a week. The doctor recognizes that there are numerous barriers for poor Romani families in accessing health care. "Poor Roma often do not pick up recipe and even buying a bus ticket poses a major expense for them. Hence, I learned not to book them for the beginning of the month before they collect their welfare. I know that they would not show up." The doctor very much appreciated the work of the health mediators: "it was so much easier for me. All is in order now, both preventive check-ups and vaccinations".

During the training of health mediators, they have reported a variety of interventions, slowly venturing even to tabooed areas of reproductive and sexual health. One could sense their genuine pride of their accomplishments.

6.2.1. Programme Assessment

Strong Support and Solid Coordination

The programme's success lies in strong logistic and personal support of the mediators from by regional and central coordinators. Regular monthly meetings strengthen this support as well. In addition, health mediators write and publish a regular newsletter as their own initiative.

Independence

Interviewed project coordinators, as well as health mediators, concurred that the key precondition for their success is their independence from both self-governance as well as the State administration. As they are employed by an NGO, health mediators are unaffected by threats and manipulations from mayors (who often end up dominating and controlling the work of social workers on State payroll).

Particularly notable are the indirect effects of the programme, such as the increased Roma empowerment at the local level. Health mediators promoted numerous changes, such as forcing the municipality to follow their obligations, specifically developing a source of drinking water and ensuring regular garbage collection. *Serving as a control mechanism towards municipalities can help to prevent manipulative and discriminatory treatment of the marginalized Roma*. For instance, one health mediator reported to the project coordinator that the mayor was refusing lunches to children whose parents owed the

municipality money. According to valid legislation, children whose families are in material need receive free lunches paid for by the State regardless of their parents' financial obligations. The project coordinator alerted MESRaS SR, and the mayor's discriminatory practice was soon discontinued.

Internal Change

Health mediators have the potential to act as agents of change towards both the marginalized Roma as well as the health-care system. This report noted that the health-care system and standardized practices that health-care providers follow are simply insufficient to help a marginalized group such as the Roma. Health mediators, often by intuition, develop solutions to address the needs of people living in rather extreme circumstances.

Moreover, there are some practices, perhaps even culturally determined ones, which may have negative impact on Roma health. Belák, for instance, notes the recovery process that is routinely neglected by Roma living in settlements. Although one may argue whether such practices are culturally or socioeconomically determined, mediators have the potential to transform them if they gain sufficient recognition within the community. Although the transformative impact can be still debated, at this stage it is clear that the programme stands as a major source of individual and possibly collective Roma grassroots empowerment. It helps people to help themselves in the most personal aspects of their lives.

6.2.2. Future of the Programme

During the preparation of this report, the programme's funding was secured until 31 December 2015. It is not clear, however, how the programme would continue after this date. According to interviewed OGPRC officials, it was vital for them to ensure a systematic and a sustainable approach. Andrea Bučková from OGPRC believed that Healthy Communities served merely to temporarily bridge the older State programme over to a new programme using EU funds. The programme of heath mediator, they believed, should have a form of a national project using EU funds. Such programme is currently implemented on a similar scheme in case of the social field workers. The social fieldwork uses funds allocated under the priority axis 4 of the Operational Programme Human Resources from the 2014–2020 programming period starting on 1 October 2014. The national project, the OGPRC, argued should be based on the previous State initiative (i.e. the Programme of Support of Marginalized Communities), not the current NGO initiative. The OGPRC does not believe that the programme will expand in the future.

In conceiving a programme of health mediators, it is critical to take into consideration the conditions under which it is most effective in delivering its objectives. There are several key preconditions of successful implementation: quality training, recruitment of health mediators from marginalized Roma and independence from municipal structures (i.e. health mediators being employment by an independent agency or an NGO, not municipalities). There is a risk of losing the current independence of the health mediators

²¹⁸ See in more details appendix 2 and section Programming Period 2014–2020.

to deliver positive changes at local level, if they are employed municipalities. While recognizing the aspect of independence in health mediator's work, OGPRC officials claimed there were some drawbacks of the current programme organization. According to the interviewed OGPRC representative, often the distribution of competencies between health mediators and social field workers was not clear, causing overlap or situations "when everyone is doing everything and no one is doing anything." Even if municipalities would employ health mediators, she believed that similarly to the programme of social field workers, there is an additional layer of governance that can ensure independence of their work. By contrast, the MHC official stressed that the programme is organized independently to prevent undue influence from mayors.

Finally, the office representative explained that in the upcoming programming period of using structural funds (i.e. 2014–2020) centrally targeted settlements are those with the highest index of underdevelopment to be calculated on the basis of the updated Atlas of Romani Communities. This means that out of 500 locations with the lowest living standards, approximately 150 would be selected for the most intense intervention, including participation in the Healthy Communities programme. She believed that there was only 50 per cent overlap with the current programme of Healthy Communities in terms of their outreach. However, as ACEC explained before the inception of the programme, the locations list was discussed and agreed upon with OGPRC. OGPRC has proposed localities that in their view merited this intervention.

6.2.3. Conclusions

The health mediation programme is the only State-funded initiative to address a complex set of problems related to Roma health and access to health-care services. Indeed, in practice it is the only initiative fulfilling the State commitments stemming from the Revised Action plan and the NRIS. The programme has great potential to address neglected fields such as preventive care, childcare, sexual and reproductive care, as well as access to specialized services. A notable additional value that would be too irresponsible to overlook is the programme's potential to act as a control mechanism over municipal and State administrations' neglect of Roma rights and basic needs. The potential to deliver change in marginalized Roma's practices that may be detrimental to people's health cannot be downplayed either.

Over more than a decade, the State administration has been unable to institutionalize the programme and ensure sustainable funding with a clear methodology and a system of continual training of health mediators. This happened despite the positive experiences of NGOs as well as the PHARE funded project. Moreover, it appears that the scope of the programme of health mediators, even in the current largest form in terms of number of working health mediators, remains insufficient given the even greater number of marginalized settlements.

7. CONCLUSIONS

The report finds that poor housing standards in Romani settlements, exposure to environmental hazards, long-term unemployment, extreme deprivation and poverty extracts a toll on the health of Roma – Slovakia's second largest national minority, after the Hungarians. In fact, demographic estimates of life expectancy of marginalized Roma are reminiscent of those of Slovaks in the 1950s. Available quantitative representative data gathered by intergovernmental agencies such as the UNDP, FRA and the WB reveals that the Roma tend to be more often negatively affected in their daily activities by chronic diseases. Among Roma chronic conditions, the most frequent were cardiovascular diseases, followed by respiratory diseases, joint and bone diseases, disorders of the nervous system, and mental disorders. Poor living conditions further increase the risk of infections and diseases that are almost unknown in the majority population. Maternal and reproductive health of women also deserves more attention from public health authorities.

While all Slovak citizens are legally guaranteed equal health-care protection, irrespective of their ethnic or national origin, Slovakia's health-care system produces ethnic disparities. Underfinancing and understaffing, non-commensurate staff workloads, corruption, and doctors' unwillingness to let patients make autonomous decisions in their treatment options is the most frequently cited endemic issues. Extreme poverty, spatial segregation, stereotypes, discrimination, and low health awareness make access to health-care services even more burdensome for marginalized Roma.

Since 1992, numerous governmental strategies aimed at Roma integration have also addressed health and health care. Policymakers, however, often reduce a complex problem simply to limited health awareness and lack of proper hygiene. This also holds true for the most troubling human rights violations in Slovakia's recent history — the involuntary sterilizations of Romani women. As both Romani and non-Romani human rights advocates confirmed, very little has been done to remedy and investigate this highly immoral and illegal practice. Instead, they note an intensifying trend of restrictive family policy and regulation relating to hospital stays of women after giving birth, all of which indirectly target Romani women. The State continues to justify these restrictions as necessary to ensure safety and health of the mother and her child.

Policymakers at ministries and various agencies that attempt to address inequalities in health experienced by the Roma are permanently facing budgetary constraints. The lack of specifically allocated budget for activities included in the Revised Action Plan and the NRIS is indeed one of the main deficiencies. Implementation of these two documents over the last years also revealed that tasks in the area of health are simply assigned to agencies, in particularly to OGPRC, which do not possess the necessary administrative powers, human, and financial resources to implement them. Some of the most glaring lapses are related to ensuring access to drinking water and the monitoring of health hazards in Romani settlements.

A top down approach in the drafting of policies of the Government of Slovakia appears to downplay the importance of participation of stakeholders at the local level, including Romani civil society. Policies handed down from the ministerial desks risk coming up short and not sufficiently responding to particular needs at the local level. Moreover, policymakers put little emphasis on the need to affirmatively overhaul the health-care system — everything from eliminating ingrained discriminatory practices to ensuring affordability to providing training for health-care professionals to creating a mutually respectful and discrimination free health-care environment for all, including Roma patients.

The last section of this report focused on the work of health mediators as an example of a good practice. Overview of the developments that led to the current programme – called Healthy Communities and involving almost 200 health mediators – describes the difficulties encountered in its sustainable implementation over the last decade. The current programme is implemented by *Platform for the Support of Health of Disadvantaged Communities,* and it brings together a variety of non-governmental, governmental, and private actors active in the area of health. ²¹⁹

This report's evaluation of the Healthy Communities programme argued that health mediators improve access to preventive, specialized, and emergency health-care services for marginalized Roma. What is more, health mediators hired by an NGO act as agents of control and help to promote positive changes on the ground. For example, after only a few months of the programme, because of the programme's efforts, some municipalities began to actively address issues of access to water. Moreover, health mediators recruited from the Roma living in marginalized locations, have the potential to act as agents of change in the health-care system as a whole, as well as in the lives of their clients. Close cooperation with health-care personnel ensures that parents attend preventive checkups and vaccination dates with their children. Moreover, well-meaning doctors are becoming more sensitive to Roma specific conditions and poverty. For instance, they now provide information in accessible language and book appointments after Roma that are in material receive their welfare payments.

In current policymaker discussions on the continuation of the programme, this report urges to take into account that Healthy Communities under the current structure that powers individuals within the marginal group by providing comprehensible education about the importance of health protection. In this sense, if health mediators manage to build trust and reputation, they can also act as agents of internal changes to transform the problematic health practices of their clients. In particular, a personal topic such as health is more likely to being influenced by individual empowerment than by outside agents recruited from the population at large. To achieve this salient potential and to ensure that health mediators act as a control mechanism vis-à-vis the local administration, the report concludes that it is absolutely critical to ensure their independence from the local municipal self-government. Otherwise, given the enormous power inequalities

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²¹⁹ Please see more detail at: www.ppzzs.sk/

²²⁰ See on this point generally advanced in the context of multicultural accommodation vs. gender equality in Ayelet Shachar, *Multicultural Jurisdictions: Cultural Differences and Women's Rights* (Cambridge: Cambridge University Press, 2001).

between Roma and municipal leadership that are often in place, health mediators may just become yet other agents that unintentionally even strengthen them.²²¹

Selected recommendations

While the goals of the NRIS and Revised Action Plan generally correspond to the emerging European framework, the first two years of strategy implementation indicate that future action should be geared towards four main goals:

- 1. Ensure that tasks set out in the strategy are vested with agencies that actually have the required administrative powers, capacities, and human resources to implement them. This is clearly the case with ensuring drinking water, monitoring of waste management and efforts to minimize associated environmental threats, including hazards associated with dogs, rats and similarly.
- 2. **Ensure clear and sufficient funding** for each of the tasks that requires activity outside the scope of the regular duties of relevant agencies, e.g. the MHC, PHA, OGPRC or municipalities.
- 3. The only State initiative addressing a vast number of issues preventive care, improved access to specialized medical services, water treatment, and others remains the health mediation programme. The programme, even in its current, so far the largest size in terms of involved health mediators, is limited in scope given even the greater number of Romani settlements in Slovakia. Moreover, one health mediator per settlement, especially in larger settlements, cannot reasonably fulfil all these tasks. Some of them, for instance awareness raising activities targeting vulnerable groups would be more effective if done in partnership with the relevant health care and education structures. At the same time, having one mediator per small locality may be redundant. It is important to optimize the number of health mediators according to the size of the targeted settlement.
- 4. There appear to be barriers inherent in the health-care system that make it difficult for everyone to enjoy access to quality health care. Chief among these are the overall underfunding of the system, overworked and undertrained medical staff, as well as the failure of health-care professionals to recognize patients' rights to make their own decisions about treatment and care. These obstacles place a disproportionate burden on the Roma, already suffering from low health awareness and prohibitively high health care and associated (transportation, access, etc.) costs. Moreover, some conventional practices appear to be insufficient to address the very specific needs of marginalized Roma, in particularly women for instance, mandatory hospital stays after giving birth. The State should thus abandon the discriminatory legislative trend, towards providing more culturally and socially sensitive health care.

UNDP, 2012) at 78-80.

²²¹ See on this point evaluation of the use of European Social Funds in Slovakia, Jakob Hurrle et Al., Uncertain Impact: Have the Roma in Slovakia Benefitted from the European Social Fund? Findings from an Analysis of the ESF Employment and Social Inclusion Projects in the 2007–2013 Programming Period (Bratislava:

It is imperative that these aspects are taken into consideration in the revised Action plan that is currently being prepared by OGPRC.

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Základné tézy koncepcie politiky vlády SR v integrácií rómskych komunít, adopted by Government Resolution No. 278/2003.

Zásady vládnej politiky Slovenskej republiky k Rómom, adopted as an appendix to the Government Resolution No. 153/1991.

Slovakia, Ministry of Health Care

Directive no. 4582/1972 of the Ministry of Health Care of the Slovak Socialist Republic on performance of sterilizations.

Slovakia, National Council

Act No.460/1992 Coll. Constitution, as amended

Act No. 365/2004 Coll. on Equal Treatment in Certain Areas and on Protection against Discrimination, as amended

Act No. 576/2004 Coll. on Health Care as amended,

Act No. 580/2004 Coll. on Health Insurance, as amended.

Act No. 581/2004 Coll. on Health Insurance Companies and Surveillance in Health Care, as amended.

Act No. 355/2007 Coll. On the Protection, Support and Development of Public Health, as amended.

Act No. 383/2013 Coll. on Assistance when giving birth to one child and on assistance to giving birth to two or more children simultaneously.

Act No. 414/2013 on Assistance in Material Need 2013.

Charter of Patient's Rights, adopted by Government Resolution No. 326/2001 on 11 April 2001.

Slovakia, Public Health Authority (Úrad verejného zdravotníctva Slovenskej republiky)

Informatívna správa o efektívnosti výsledkov získaných plnením 2. etapy Programu
podpory zdravia znevýhodnených komunít na Slovensku na roky 2009–2015
(Bratislava, 31 marca 2011).

APPENDIX – the Use of EU Structural Funds for Roma Health

Programming period 2007-2013

During the 2007–2013 programming period, Slovakia relied upon EU Structural Funds' Horizontal Priority – Marginalized Roma Communities (HP MRC), with an allocated budget of 200 million EUR to promote inclusion of the Roma. HP MRC shall ensure territorially targeted channelling of structural funds from six operational funds, including OP Health's allocation of EUR 10 million. In order to apply for funds, municipalities had to first prepare and have approved their local comprehensive approach strategies for development of marginalized Romani communities (MRC). These local strategies should be prepared in a participatory manner, including members of the MRC. Only municipalities listed in the Atlas of Romani Communities of 2004 were eligible to apply for funding via this channel. Once their local strategies were approved, municipalities could apply for funding within calls for proposals issued through individual operational programmes. ²²²

After delays with approvals of the local strategies, MHC SR issued its first such call only on 26 February 2010, with a deadline of 10 July 2010 and with a total allocated budget of EUR 8 million. The minimum grant for an individual project was EUR 350,000 and the maximum was EUR 2 million. The call was intended to support renovation and modernization of health-care infrastructure, including the purchase of medical equipment. Eventually 10 projects, with an overall budget of EUR 6,259,160.7, were approved for funding. All of them were regionally targeted – seven in Prešov, two in Košice, and one in Banská Bystrica. These projects sought to improve the quality of health-care services attended in part by the Roma population. The second call was issued on 30 May 2011, with a total budget of EUR 3,740,839.3. Minimum support for an individual project was set at EUR 100,000, with a maximum of EUR 2 million. Another five health-care facilities renovation projects were approved, with a total budget of EUR 3,581,883.66. No call for proposals was issued in 2012. In 2013, MHC SR issued a call for proposals with a total budget of EUR 2 million within the priority axis support of health and prevention of health risks: measure reconstruction and

²²² See e.g. System of Coordination of Implementation of Horizontal Priority Axis Marginalized Romani Communities (OGPRC: Bratislava, 2012) at 5–6, 9–10 and 14–15.

²²³ This information is available from http://opz.health-sf.sk/archiv-vyziev-2010/2-vyzva-opz-20102102-pre-polikliniky-a-zdravotne-strediska

²²⁴ This information is available from http://opz.health-sf.sk/vyhodnotenie-vyziev/2-sprava-o-vyhodnoteni-vyzvy-opz-20102102

The call is available in the archive of calls is available from http://opz.health-sf.sk/archiv-vyziev-2011/2-vyzva-opz-20112102-pre-polikliniky-a-zdravotne-strediska

²²⁶ Information about evaluation of the projects is available from http://opz.health-sf.sk/vyhodnotenie-vyziev/2-sprava-o-vyhodnoteni-vyzvy-opz-20112102

²²⁷ Information is available from http://opz.health-sf.sk/

modernization of health-care facilities. The aim of the call was to support comprehensive projects of reconstruction and modernization of health-care facilities, including the purchase of medical equipment to treat cardiovascular, respiratory, digestive, and oncological diseases. Applicable projects had to be included in the comprehensive strategies of municipalities and towns. Maximum support for one project was set at EUR 2 million with a 10 February 2014 deadline for submission. In December 2013, MHC SR increased the allocated amount to EUR 4 million, extending the deadline to 7 April 2014. ²²⁸

Programming period 2014–2020

The recently approved 2014–2020 Partnership Agreement between the Government of Slovakia and the European Commission envisages addressing the specific needs of marginalized Romani communities primarily within its priority axis 4 of the operational programme Human Resources, with assigned resources amounting to EUR 380 million. Using the integrated approach, the OP relies on a combination of ERF and ESF funds. According to the agreement, investment in education, employment, housing, and health care should facilitate Roma inclusion.²²⁹

The role and the contribution of the ESI Funds in the implementation of the integrated approach to address the specific needs of geographical areas most affected by poverty or of target groups at the highest risk of discrimination or social exclusion.

| Specific target group or geographical area | Short description of the needs | The ESI Funds that will be used | Main types of planned actions which are part of the integrated approach | Programme |
|--|--------------------------------------|---------------------------------------|--|-----------|
| In line with the inclusion of MRC, geographical areas will | Residents of MRC affected by poverty | ESF | Systematic support of children from the MRC in pre- primary education | OP HR |

²²⁸ Information is available from http://opz.health-sf.sk/archiv-vyziev-2013

²²⁹ Partnership agreement of the SR for the years 2014-2020, adopted by Government Resolution 65/2014 on 12 February 2014 at 286. Certain aspects of the Partnership Agreement has been accepted by the EC on 20 June 2014, C (2014)4134 final.

| Specific target group or geographical area | Short description of the needs | The ESI Funds that will be used | Main types of planned actions which are part of the integrated approach | Programme |
|---|---|---------------------------------------|--|-----------|
| be identified at the level of self-governments. Eligible territories will be | social exclusion due to unequal access to | | Consultancy for the transition between the levels of education (from kindergarten to primary, from primary to secondary), including parental involvement | |
| those local governments employme included in the Atlas of Roma health care | employment and | | Support for second chance education programmes, with an emphasis on those that are directly linked to the labour market | - |
| | | | Promoting systematic provision of social and assistance services aimed at increasing the employability of people living in MRC (i.e. field social workers, community workers/workers in social services) | - |
| | | | Support of innovative programmes aimed at increasing local employment through the support of social economy entities | |
| | | | Support of existence and functioning of community centres in municipalities with the presence of MRC | - |
| | | | Promoting systematic provision of services and assistance through the programme of community workers in health education in communities involving separated and segregated MRC | - |

| Specific target group or geographical area | Short description of the needs | The ESI Funds that will be used | Main types of planned actions which are part of the integrated approach | Programme |
|--|--------------------------------|---------------------------------------|--|-----------|
| | | | Support of programmes aimed at achieving a higher hygiene standard of marginalized Roma settlements and systematic reduction in the number of illegal dwellings characteristic with extremely low level of hygiene standards through the provision of technical assistance to municipalities involving MRC aimed at settling land Assistance programme to municipalities involving | |
| | | | MRC aimed at increasing the absorption of the ESI Funds | |
| | | ERDF | Promoting ladder housing programmes in social mobility and integration of the MRC members (construction and reconstruction of dwellings) | OP HR |
| | | | Promoting access to drinking and sanitary water in separated and segregated MRC environment with an emphasis on low cost measures such as drilling and digging wells | • |
| | | | Promoting construction, reconstruction and modernization of preschool facilities | • |

| Specific target group or geographical area | Short description of the needs | The ESI Funds that will be used | Main types of planned actions which are part of the integrated approach | Programme |
|--|--------------------------------|---------------------------------------|---|-----------|
| | | | Promoting construction, reconstruction and modernization of community centres | |
| | | | Promoting micro financial instruments | |
| | | | Supporting the reconstruction and construction of premises of social economy entities | |

Contribution of the OP Human Resources to solving specific needs of geographical areas/target groups most affected by poverty.

Systematic support of children from the MRC Residents of MRCs Eligible territories will be in pre-primary education. those local governments Systematic support of educational, training included in the Atlas of and free time activities for children from MRC with focus on their mainstreaming. Roma communities reporting a defined level Promoting systematic provision of social and of segregation index. assistance services in municipalities involving MRC aimed at increasing of the employability of MRC (i.e. field social workers, community workers / workers in social services). Support of innovative programmes aimed at Social and increasing local employment through the economic promotion of social economy entities integration of Less Support of existence and functioning of Integration of marginalized developed **FSF** community centres involving MRC MRCs communities region Promoting systematic provision of services such as the and assistance through the programme of Roma community workers in health education in communities involving separated segregated MRC. Support of programmes aimed at achieving a higher hygiene standard of marginalized Roma settlements and systematic reduction in the number of illegal dwellings characteristic with extremely low level of hygiene standards through the provision of technical assistance to municipalities involving MRC aimed at

settling land.

| | Assistance programme to municipalities involving MRC aimed at increasing the absorption of the ESI Funds. | | | | | |
|---|--|-----------------------------|----|---|------|-----------------------------|
| Residents of MRC Eligible territories will be those local governments included in the Atlas of Roma communities reporting a defined level of segregation index. | Promoting ladder housing programmes in social mobility and integration of the MRC members. Promoting access to drinking and sanitary water in separated and segregated MRC environment with an emphasis on low cost measures such as drilling and digging wells Promoting construction, reconstruction and modernization of preschools facilities Promoting construction, reconstruction and modernization of community centres. | amenities municipalities | in | Provision of support for physical and economic regeneration of deprived urban and rural communities | ERDF | Less developed region |
| Residents of MTC Eligible territories will be those local governments included in the Atlas of Roma communities reporting a defined level of segregation index. | Supporting the purchase of equipment, technologies and licences necessary to implement a business plan by a social economy entity, with an emphasis on the use of micro-loans. | amenities municipalities | in | Providing support to social enterprises | ERDF | Less developed region |

Source: Partnership Agreement at 289–290.

Within this priority axis, Office of the Government Plenipotentiary for Romani Communities (OGRPC) further proposes the use of so-called "take away packages" method for areas identified as the least developed. These take away packages will target three areas of intervention social work and services (including social field, work, community centres and health mediators), education (pre-school education) and housing (legalization of property titles underneath settlements and access to drinking water). These interventions will be divided into seven national projects, while

the recipients of such financial aid would be municipalities. During the preparation of this report, more accurate information was not available.²³⁰ Details of this proposal remain subject to on-going negotiations.

 $^{^{\}rm 230}$ Comments to this report provided by the OGPRC on 6 June 2014.