# Roma Health Mediators

SUCCESSES AND CHALLENGES





## Roma Health Mediators:

## Successes and Challenges

October 2011

Roma Health Project

Open Society Public Health Program



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Cover photo: A Roma Health Mediator speaks with a client in Serbia.

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# Acknowledgement

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This report would not exist were it not for the pioneering work of Roma Health Mediators and the NGOs and governmental agencies that support them. We are thrilled to see the development of a real grassroots initiative driven by Roma NGOs and adopted by government agencies. The mediator profession is a new and exciting opportunity–particularly for Roma women–within the labor market. This is a positive step not only for improving health care for individuals but also for enhancing integration of the Roma.

As discussed throughout this report, there are some challenges to advancing the Roma Health Mediator model, and the number of mediator jobs is tiny in comparison to the health needs of Roma communities. There is also a fear that decentralization of health services might lead to segregated, poor quality health care for Roma patients. The Roma Health Project will continue to address these challenges and advocate for the future sustainability of Roma Health Mediation programs in our focus countries.

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## Introduction

The Roma Health Project of the Open Society Foundations has supported Roma health programs since January 2001. The project works to advance the health and human rights of Roma people by building the capacity of Roma civil society leaders and organizations and advocating for accountability and a strong civil society role in the design, implementation, and monitoring of policies and practices that most impact the health of Roma.

Many countries where the Roma Health Project is active have Roma Health Mediator (RHM) programs. RHMs are members of the Roma community who are trained to liaise between the community and the health system. In addition to Roma Health Mediators, some countries, such as Albania, Finland, Greece, and Serbia, have mediators who facilitate access to employment, education, or public services more generally.

In 2005, the Roma Health Project published a qualitative study of the Roma Health Mediator model, focusing on Bulgaria, Finland, and Romania. The study report, *Mediating Romani Health*, included findings specific to each country, as well as overall findings about Roma health mediation. In general, the study revealed that RHMs have greatly assisted individual Romani clients. However, policymakers fail to capitalize on these successes. They do not involve Roma Health Mediators, who are very knowledgeable about community health needs, in developing programs and strategies for Roma health. In addition, they do not use the information gathered during the program to guide further work. Finally, Roma health mediation can address few of the structural inequities that shape Roma health in the first place. To maximize impact, Roma health mediation programs should be implemented in conjunction with other programs to address poverty, discrimination, and health equity.

The present report is an update of the 2005 study. An updated report was necessary for several reasons:

- Roma health mediator programs continue to be one of the most frequently used programs to improve health among excluded Roma communities in both Western and Eastern Europe. Therefore, assessing program effectiveness and the factors that make health mediation more or less successful is important to promoting Roma health mediation program effectiveness. Many Roma Health Mediator programs have started since the previous report was written, including in Macedonia, Serbia, and Ukraine, providing new program models to assess. Other RHM programs, namely Bulgaria's and Romania's, have grown substantially since 2005, providing examples of how RHM programs can become institutionalized within the national health system.
- As compared to other sectors related to Roma inclusion, such as education, Roma health is one of the domains with the fewest programmatic successes. International donors as well as national governments have allocated comparatively less funding to Roma health, and few program models exist.<sup>2</sup> However, in the last several months, the Council of Europe and other organizations have increased financial investment in RHM programs. Undertaking a study that highlights the successes and challenges of RHM programs will inform Roma health programming and encourage effective use of the funds committed.
- In the face of the global financial crisis and persistent low governmental commitment to improving Roma health, some countries are cutting back or under-funding RHM programs. This threatens the continuation of one of the few existing Roma health interventions. Outlining the existing effectiveness of RHM programs will provide important information to advocates and to governments.

The following RHM study report summarizes study objectives, the international policy context, key determinants of Roma health, and study findings. General study findings are presented first. The general discussion includes few examples from Macedonia or Ukraine, as these programs are not yet finalized or have just begun. The report then provides country specific program summaries and findings. Recommendations are provided for each country as well as for Roma health mediation programs overall.

# Study Objectives and Methodology

The study has the following objectives:

- To qualitatively assess (and quantitatively review, insofar as possible) the health service access impact of Roma health mediation programs in Romania, Serbia, and Slovakia, and to a lesser extent, in Bulgaria, Macedonia, and Ukraine. "Health service access" includes outcomes related to health care utilization, insurance coverage, possession of personal documents such as identity cards and birth certificates, vaccination inclusion, knowledge about health entitlements, and so on.
- To analyze the health service access impact of Roma health mediation programs in the context of other national programming related to Roma health and to health equity.
- To analyze the international policy context, including political and policy processes relating to the Decade of Roma Inclusion, the EU accession process, the EU Roma Platform, and the Council of Europe. The larger context of increased attention to health equity in Europe is also discussed.

- To describe the key features of RHM programs in each of the six countries, including, but not limited to how many RHMs are employed, who trained them, how they were trained, how they are supervised, who pays them, their relationship with local physicians and other health providers, and their relationship with local authorities.
- To assess challenges and barriers to further development and expansion of RHM programs in each country.
- To identify the limitations of RHM programs. What determinants of Roma health is mediation unable to address?
- To develop country level and general recommendations that can guide the development of sustainable, effective Roma health mediation programs.

These objectives were realized through several different activities, including: (a) an academic and grey literature review, (b) qualitative field assessments in 6 countries, and, (c) discussions with pertinent representatives and activists.

The qualitative field assessments were carried out by the report author and expert consultants hired in each country. In focus countries, which included Romania, Serbia, and Slovakia, consultants interviewed key stakeholders and conducted a focus group with between 4 and 10 RHMs. Roma Health Mediators were also asked to complete a brief questionnaire regarding the frequency with which they encountered certain situations (see Annex 1). Focus groups and questionnaires were not conducted in secondary countries, Bulgaria, Macedonia, and Ukraine. All of the information contained in this report comes from consultant reports for the 6 countries, except where otherwise noted with an endnote.

This report targets several key audiences, including international and national donors, program planners, and NGOs addressing Roma inclusion and/or health equity. The recommendations were developed in order to guide these entities in their work related to Roma health mediation, as well as Roma health more broadly. Indeed, discussion regarding the international policy context suggests funding streams and policy mechanisms that might be employed to promote Roma health mediation and other health equity programs.

## 3. International Policy Context

There are several pertinent international policy mechanisms, including: the Decade of Roma Inclusion, the EU accession process, the EU Roma Platform, and the Council of Europe. These mechanisms operate in the context of increased attention to health equity in Europe.

#### 3.1 Decade of Roma Inclusion

The Decade of Roma Inclusion is a multilateral policy initiative aiming to remedy longstanding Roma exclusion. Governments of countries with large Roma populations voluntarily join the Decade as part of their commitment to improving the status of their Roma citizens. At present, 12 countries have jointed the Decade. International agencies and NGOs, including the United Nations Development Program (UNDP), UNICEF, the World Health Organization (WHO), the Council of Europe, the World Bank, Open Society Foundations, the European Bank of Reconstruction and Development, and others also participate. All of the countries included in the current study are members of the Decade, with the exception of Ukraine.

A Steering Committee comprised of governmental representatives, Roma leaders and activists, multi-lateral donors, and international organizations identified 4 Decade focus areas: (I) education, (2) employment, (3) health, and (4) housing. They also named 3 cross-cutting themes: (I) income poverty, (2) discrimination, and (3) gender.<sup>3</sup>

Participating governments have developed a National Action Plan (NAP) for the respective focus areas, including health. Many of these action plans include a Roma Health Mediator project. Other health-related activities foreseen in the health action plans include health data collection, training of health professionals to work with excluded Roma communities, and vaccination campaigns.

Many countries have been criticized for not developing rigorous NAPs, for not adequately involving civil society and Roma communities in NAP development, and for not implementing the NAPs they developed. However, the Decade also provides an opportunity for advocates and program planners to share experiences about common programs and challenges, and to hold governments accountable. Advocates can point to NAPs and highlight when governments fail to implement activities they committed to implementing. The current report is part of the wider debate regarding the Decade; the report can serve as a technical resource and as a tool for advocates who wish to demonstrate the efficacy of Roma health mediation.

#### 3.2 EU Accession Process

Several countries in Central and Eastern Europe have recently joined the EU, or are in the process of joining. Of the countries covered in this report, Slovakia joined the EU in 2004, and Bulgaria and Romania joined in 2007. Macedonia is a candidate country, and Serbia is a potential candidate. Ukraine is not pursing EU membership.<sup>4</sup> Before becoming members of the EU, candidate and potential candidate countries are eligible for pre-accession assistance. Some of these instruments have been used to fund Roma health mediation programs. For example, Romania and Slovakia received PHARE assistance for Roma health mediation (and other) activities.<sup>5</sup> Moreover, once countries are EU members, they have access to European Structural Funds, including the European Social Fund. Slovakia has used European Social Fund monies to support the RHM program.

The structure of EU funding is thus relevant in a critical assessment of RHM programs. The text box at right outlines some publications that contain in-depth discussions about how EU funding can better promote health equity and Roma inclusion.

#### EU Funds, Health Equity, and Roma Health

The World Health Organization (WHO) and OSF have issued reports regarding the use of EU funding. A summary of the key findings of each follows.

WHO's report entitled, How Health Systems Can Address Health Inequities Through Improved Use of Structural Funds, focuses on health equity, rather than just Roma health. WHO found that European Social Fund management and service delivery require greater focus on health equity. Specifically, the report authors call for the inclusion of health equity indicators in structural fund planning in Brussels. This would promote the inclusion of health equity activities in all structural fund projects, and would ensure that the European Commission tracks how well the projects they fund promote health equity. In addition, the authors suggest that project proposals include health equity indicators, as well as capacity building activities that would enhance country ability to measure and promote health equity. The full report can be found at: http://www.euro.who.int/\_\_data/assets/ pdf\_file/0007/129868/e94606.pdf.

The European Commission has acknowledged that Member States "do not make yet sufficient use of available EU funds to address the needs of the Roma" (European Commission, 2011). OSF recently published Making the Most of EU Funds for Roma: A Compendium of Good Practice. This report covers EU funding for many kinds of Roma inclusion projects—not just health. The report indicates that many evaluations of Roma inclusion projects funded with EU money concluded that these projects were top-down, with insufficient Roma participation. Complex application procedures and administrative rules made it difficult for community organizations to participate. Funding for each project was sometimes too little to have a great impact, and projects were too often standalone efforts, separated from governmental policies and institutional structures. Moreover, many were very short-term, so they had little long-term impact. Making the Most of EU Funds for Roma presents projects that overcame these challenges. The full report can be found at: http://www.romadecade.org/files/ftp/Publications/Harvey%20-%20 Making%20the%20Most.pdf. Subsequent OSF policy analysis suggests that the European Commission Directorate General for Health and Consumers has done a poor job of integrating lessons learned from previous Roma health projects that they have funded. Collating these lessons is hampered by lack of transparency, as there is no central database of EU funded projects.

#### 3.3 The EU Roma Platform

As noted in the introduction, the EU is increasingly focusing on addressing the continued Roma exclusion, as progress in the first half of the Decade of Roma Inclusion has been inadequate. The EU Roma platform is one manifestation of this increased focus. The Platform aims to strengthen EU level and Member State action on Roma exclusion. The first Platform meeting was held in Prague in 2009. National governments, the EU, international organizations, and civil society representatives attending agreed on 10 common basic principles on Roma inclusion. The 10 common principles are:

- Constructive, pragmatic and non-discriminatory policies
- 2. Explicit but not exclusive targeting
- 3. Inter-cultural approach
- 4. Aiming for the mainstream
- 5. Awareness of the gender dimension
- 6. Transfer of evidence-based policies
- 7. Use of community instruments<sup>6</sup>
- 8. Involvement of regional and local authorities
- 9. Involvement of civil society
- 10. Active participation of the Roma<sup>7</sup>

All of these principles can be applied to Roma health mediation programs. Principle 2—explicit, but not exclusive targeting—is particularly relevant. Governments should maintain robust universal health and social protection services that everyone can access, but they should also create particular programs for the Roma to compensate for entrenched disadvantage and marginalization. This approach is consistent with the findings of the WHO Commission on the Social Determinants of Health. Following a global evidence review, the Commission concluded that promoting equity means more than just treating everyone the same. Services may need to be adapted or created to serve particular groups, especially those that experience marginalization. Targeted programs should be sustainable. Short term efforts will not have an impact on longstanding inequity. Fostering real inclusion will require long term programs that are linked to other governmental efforts, such as educational programs, efforts to measure and promote health equity, and infrastructure projects. Roma health mediation can be understood as one such targeted measure. Roma health mediation helps an excluded group benefit from universal health services.

As part of the EU Roma Platform, the European Commission issued a European Framework for National Roma Integration Strategies. The Framework sets goals for progress in education, employment, health, and housing. Before the end of 2011, EU governments should submit national Roma strategies outlining how they plan to advance these goals. In terms of

health, the Framework specifies that governments should aim to decrease the gap in health status between Roma and the population overall.9

The European Commission will also identify ways to ensure that EU funds are more effectively used to promote Roma integration. Finally, the Commission plans to establish a monitoring mechanism to measure results of activities specified in the National Roma Integration Strategies. 10 The need for better measurement is acute. In a 2010 report entitled No Data, No Progress the Open Society Foundations explained that "the lack of data about Roma communities remains the biggest obstacle to conducting any thorough assessment of how governments are meeting their Decade commitments, despite widespread agreement among participating governments about the crucial need to generate data disaggregated for ethnicity in order to assess and guide policies." Indeed, in their communication on health inequalities in Europe, the European Commission asserted that "measurement of health inequalities is a fundamental first step to effective action."12 Lack of data inhibits understanding of Roma exclusion and health inequity, and makes measuring progress impossible. Indeed, the current study on Roma health mediation is limited by lack of data. RHMs may monitor their own activities, but it is impossible to measure changes in health care access or health status without ethnically disaggregated<sup>13</sup> baseline data. Many Decade Action Plans include the collection of disaggregated health data, but few governments have taken concrete steps to collect such information. No Data, No Progress discusses why governments have failed to improve data collection systems and offers concrete recommendations.

### 3.4 Council of Europe

The Council of Europe is an intergovernmental organization. It is much larger than the European Union, and includes all countries in Western, Central, and Eastern Europe. Council of Europe members include countries that are not in the EU that have significant Roma populations, such as Ukraine. In the past, the Council of Europe has issued recommendations related to Roma health, such as the Recommendation to member states on health services in a multicultural society<sup>14</sup> and the Recommendation on the adaptation of health care services to the demand for health care and health services of people in marginal situations.<sup>15</sup> The European Court of Human Rights, which is part of the Council of Europe, has also issued judgments related to Roma health and rights.

In October 2010, Council members issued the Strasbourg Declaration, following a high level Council of Europe meeting on the situation of Roma. The Declaration contained a list of priorities and Council of Europe actions. One Council of Europe action was to: "set up a European Training Programme for Roma Mediators with the aim to streamline, codify and consolidate the existing training programmes for and about Mediators for Roma, through the most effective use of existing Council of Europe resources, standards, methodology, networks and infrastructure, notably the European Youth Centres in Strasbourg and Budapest, in close co operation with national and local authorities."<sup>16</sup>

The Council of Europe has already begun to provide this training to mediators working in several domains, including health, education, and employment. They have provided phase 1 of the 7-day training sequence in several countries, and will provide phase 2 before the end of the year. Importantly, local stakeholders, such as school, health facility, public health, and employment officials participate in a portion of the trainings. In order to complement, rather than replicate training already received, the Council of Europe training focuses on human rights and empowerment. The Council of Europe reports that their work will likely include the creation of some European-wide fora on mediation as well as a code of ethics for mediators. In July 2011, the Council of Europe and the European Union announced a €1 million Euro partnership to continue and expand this mediator work. Funding will be used primarily to conduct additional training. Unfortunately, it does not appear that any of these funds can be used to provide salary support—a growing priority in several countries. Indeed, Roma health mediator program sustainability is perhaps the key challenge at present, making salary funding the key priority.

### 3.5 EU Health Equity Strategy

In 2006, the Council of the European Union adopted conclusions on common values and principles in European Union health systems. These conclusions specified that: "The overarching values of universality, access to good quality care, equity, and solidarity have been widely accepted in the work of the different EU institutions." This attention to equity is reflected in the EU's most recent health strategy. EU strategies are relevant for Member States as well as candidate and potential candidate countries, which are seeking to make their policies consistent with EU standards as part of the accession process.

The WHO, too, has increasingly focused on health inequalities in Europe, including examining how they impact excluded Roma. WHO Member States in Europe include all of Western, Central, and Eastern Europe as well as the countries of the Former Soviet Union (*i.e.* all of the countries included in this RHM study). WHO's Office for Investment for Development and Health conducted a poverty and health technical consultation in 2009 that included Roma as one of three focus groups. This consultation included the writing of a comprehensive background paper on Roma health, as well as several case studies on Roma health projects.<sup>21</sup> In addition, WHO has commissioned a two-year European Review of social determinants and the health divide across Europe. This review will include a Roma health-specific component.<sup>22</sup> Finally, in June 2011, WHO officially joined the Decade of Roma Inclusion.

WHO has also engaged in related country work. It worked closely with the Macedonian Ministry of Health to identify challenges and opportunities related to the Decade Action Plan

and sponsored a Roma health conference in Skopje. In Serbia, WHO conducted an environmental health assessment focused on Roma communities and initiated the innovative SWIFT project.

#### **SWIFT Project**

The SWIFT Project was designed by WHO, and is implemented through a partnership among WHO, International Organization for Migration, United Nations Office for Project Services, local and national authorities, and the Roma community of Serbia. The project is based on the observation that informal garbage collectors and recyclers (most of whom are Roma) faced insecure income and many workrelated health hazards. They were also vulnerable to exploitative middle men who paid them too little for what they had collected. With financial support from the Government of Norway, the project has entailed the establishment of a recyclers' cooperative, and the construction of a recycling center that limits worker exposure to dangerous waste. As a result, recyclers have direct access to a recycling center, and no longer rely on middle men. Their incomes have risen, and their health has improved. Moreover, the project includes health assessments of the Roma communities served, and later phases of the project will include action on the health issues identified. For more information, see: http://www.swift.rs/eng.

Increased attention to health inequities is important because advocates can refer to these frameworks and commitments in advocacy. Moreover, focus on health inequities will influence European funding mechanisms to be more oriented to promoting equity. Finally, increased governmental capacity to document and remedy health inequities will provide a sound institutional basis for action on Roma health. Rather than just implementing standalone projects to improve Roma health, countries can promote equity in all of their health programs, ensuring a more comprehensive approach to closing the health gap between Roma and the overall population, and to ending health disparities more broadly.

## 4. Roma Health Conditions

While conditions in the countries included in this study vary, as a group, Roma have poorer health status and worse health service access. Although few countries have national level Roma health data, peer-reviewed articles report that Roma are disproportionately unvaccinated; have poorer than average nutrition; and experience higher rates of low birth weight births, for perinatal mortality, and tuberculosis. Lack of access to health care exacerbates poor health status. Roma may not have adequate access to care because they lack identity cards or other documents required to obtain health insurance, do not have sufficient funds to pay for transport to health facilities or other healthcare related costs, or, because they have experienced or heard about discrimination in health care settings. In fact, 20% of Roma responding to a European Union Fundamental Rights Agency survey reported that they had experienced discrimination in health services in the past year.

Roma are disproportionately poor, and they are concentrated among the most poor. For example, when multiple levels of poverty were established among groups surveyed in Bulgaria, Hungary and Romania, Roma were overrepresented in the poorest groups. However, poverty alone does not account entirely for the worse health indicators among excluded Roma. The fact of being Roma makes one at greater risk for ill health.

There has been inadequate research among the Roma minority in Europe, but data from Europe and the United States show that racial differences in health cannot be accounted for entirely by socio-economic status.<sup>31</sup> Individual and institutional discrimination,<sup>32</sup> substantial residential segregation,<sup>33</sup> poor living conditions, forced evictions, and experiences of violence<sup>34</sup>

are just some factors that likely make Roma vulnerable to ill-health beyond what their socioeconomic status would suggest. In other words, Roma likely have worse health than other poor people with the same income level. The few studies that have been conducted among the Roma confirm this finding. One study found that, among children between o and 2 years, the incidence of influenza, ear infections, intestinal infections, and viral diseases was significantly higher among the Roma than among the ethnic majority population of a comparable socioeconomic status.35 In brief, poor Roma children experienced worse health than non-Roma who were poor. Similarly, another study concluded that, considering average income, educational attainment, unemployment, and percentage of the population living in excluded Roma settlements, the percentage of the population living in excluded Roma settlements was the most important factor in shaping regional mortality rates of children under the age of one.<sup>36</sup> This means that regional variation in child death rates was best explained by the percentage of the population living in Roma settlements, rather than other measures of socio-economic status. Finally, a recent data analysis in Serbia found that Roma children were significantly more likely to experience an acute respiratory infection than either the general population or the poorest quintile of the general population, not including the Roma.<sup>37</sup> Again, this means that Roma in particular—not just the poor—are at risk.

A survey conducted by the Slovak government on excluded Roma communities illustrates the deprivation that can characterize ghettoized settlements. The government surveyed all excluded Roma communities (not all Roma live in such communities, just the most disadvantaged). Eighty one percent lacked sewage systems, 37% lacked water supply, and almost I/3 of the houses were illegal, meaning that the households concerned were ineligible for state assistance to improve their habitation. Also, many of these settlements are on unpaved roads and are not served by public transport, making access to medical and social services difficult.<sup>38</sup>

The relevance of Roma ethnicity in shaping health status illustrates the need for health programs focused specifically on Roma. While it is very important to ensure that health services are affordable for the poor, this is not enough to close the health gap between the Roma and the overall population. Targeted programs, such as Roma Health Mediation, are required.

## 5. Roma Health Mediation

Roma mediation was started as a community conflict mitigation program in 1992 in Romania, based on a French model. The initiative was pioneered by Romani Criss, a Roma NGO.

## 5.1 Roma Health Mediator: Job Descriptions

Official RHM job descriptions vary little by country, although the actual work may vary. In general RHMs are required to:

- Assist individual clients in obtaining personal documentation and health insurance.

  This is a need in all countries except for Slovakia, where almost all Roma have documentation and health insurance coverage.
- Assist (and encourage) individual clients to go to the doctor. This may entail explaining to clients the importance of preventive care, educating clients about the costs for particular services and ensuring that they are not asked to pay more, and providing linguistic translation during consultations. Focus group transcripts from Romania and interviews with program planners in Bulgaria and Serbia show that RHMs spend a good deal of time on this task. In cases where RHMs accompany clients to the doctor, they may also follow up with clients later. RHMs might ensure that clients are taking

prescribed medicines, that they return to the doctor if they still feel ill, and so on. RHMs in Bulgaria reported frequently helping clients to pay less for services if they are entitled to do so (*e.g.* for being officially unemployed, etc.)

- Assisting local health authorities with particular health campaigns, particularly related to vaccination. In some countries, RHMs tell families about the importance of vaccination, and facilitate vaccination campaigns in Roma communities. In some countries, they may attempt to locate families who have failed to bring in a child for a scheduled vaccination. In these cases, either family doctors or health authorities provide RHMs with the names of those who are due for vaccination.
- Refer clients to relevant health, social, and educational services. RHMs may actually accompany clients to health or social service offices, or they may simply refer them to the appropriate place. If there is no other professional playing this role, RHMs can aid clients in obtaining social assistance services to which they may be entitled. They may also encourage parents to enroll their children in school, and assist parents in understanding and completing the relevant forms and vaccinations. (Some countries have education specific mediators who fulfill these tasks).
- Conducting health education sessions in the community. Such sessions may include inviting women to attend lectures on topics related to maternal, reproductive, and child health, informing individual families about the importance of preventive care, and lecturing school children on healthy lifestyles. Reproductive health in particular is often a focus. According to research recently conducted by Romani Criss, more than three quarters of the Romanian RHMs spend most of their time on this task.
- Providing targeted health assistance. Roma Health Mediators in a few countries have been taught to monitor blood pressure. Others provide observation and support to Roma patients on TB treatment. No RHM program includes first aid or direct medical care.
- Providing legal referrals for individual clients who have experienced discrimination or other human rights violations in health care settings. RHMs in almost all countries have had some training related to patients' rights. They also have been trained in health and social protection rights and entitlements and are aware if patients are charged more than they should be for particular services. In these cases, RHMs might refer clients to national anti-discrimination bodies, such as an ombudsman or the Bulgarian Committee for Protection Against Discrimination,<sup>39</sup> or to NGOs that work on Roma rights. In focus groups, RHMs report encountering at least some cases of discrimination and abusive language in health care access or provision.

It is important to note that almost all programs can only use process indicators to monitor the above activities. In other words, RHMs can record how many health education sessions they conduct, or how many patients they assist in going to the doctor. However, because countries do not keep disaggregated health data, there is no way of knowing if more Roma are going to the doctor than before, if health status is better in Roma communities that are served by RHMs, and so on. Instead, we have to rely on indirect data, such as reports from local physicians (who can report if they are seeing more Roma patients than before), reports from RHMs and Roma community members, and national data on the number of new adults with health insurance coverage. As noted earlier, this lack of data hinders careful analysis of Roma health, as well as monitoring of program efficacy.

#### 5.2 2005 Study Findings

The 2005 study by the Open Society Foundations identified several common strengths and challenges in the ability of Roma Health Mediators to carry out their necessary tasks. Many of these strengths and challenges are still relevant. In brief, the 2005 study concluded:

"RHMs have greatly assisted individual Romani clients...RHMs reduce bureaucratic and communication obstacles to improved health by facilitating patient/doctor communication and assisting clients in navigating bureaucratic procedures relating to health insurance and social assistance. Additionally, RHMs do a fairly good job communicating with the Romani community by visiting the ill and convincing them to visit the doctor, encouraging pregnant women to get prenatal care, informing the community about family planning and how to prevent sexually transmitted infections, and reminding individuals of the need for child vaccination."40

"While this work helps to improve the health of Romani individuals, the study team did find a risk posed by RHMs continuing to fill a communication gap between clients and medical providers—both clients and physicians could become dependent on the RHMs. Instead of encouraging doctors to adapt a health promotion approach of enhancing patient health literacy, Roma health mediation could actually relieve doctors from passing on essential information in a manner that a patient understands. Paradoxically, Roma health mediation may serve to increase the distance between patient and doctor, and, unless the RHM seeks to educate the patient, may perpetuate the need for health mediators..."

"Existing mediator programs currently fail to remove certain obstacles to more effective patient/doctor interactions, or to ameliorate social determinants that have a negative impact on Romani health. These include discrimination, patient financial limitations, flawed legislation, the particular needs of doubly marginalized groups, and inadequate political will. Mediator programs could be changed to better address some of these factors. However, other components of Romani health strategies must provide the main programming, political impetus, and resources to reduce or remove these obstacles."<sup>41</sup>

"Moreover, program results have not been effectively leveraged to bring about systemic change, and program activities are not sufficiently oriented toward remedying the structural inequities that shape Romani health in the first place. Moreover, some of the mediation programs studied are undertaken in isolation and are not accompanied by necessary legislative changes nor are they adequately integrated into the overall public health system."

Fortunately, some of the challenges noted above have been addressed in some countries. Macedonia and Serbia, for example, have changed legislation related to documentation and health insurance coverage, making it easier for Roma to obtain both. However, obstacles remain in Macedonia; those classified as "habitual residents."<sup>43</sup> face enormous difficulties in obtaining citizenship and residency—a pre-requisite to obtaining health insurance.

The Council of Europe training focuses on human rights and empowerment. This will help mediators to promote health autonomy among their clients, rather than allowing them to passively receive services. Some RHMs have received training specific to disability, helping them to deal with this doubly marginalized population. At the same time, as will be shown, new problems have arisen. For example, longstanding programs, particularly in Romania, are in danger of being downsized prematurely due to budget cuts and lack of commitment to Roma health mediation at the local level. Other programs, such as the Slovak program, have failed to grow or even to become sustainable; persistent lack of commitment and funding have compromised the effectiveness of mediator programs from their inception.

The following pages describe issues to consider in designing RHM programs, RHM program successes, and challenges. These successes and challenges are presented in the context of international policy and of the findings of the 2005 study.

Table I is intended to give readers a rough idea of the number of RHMs per 10,000 Roma inhabitants. The population figures are approximate, and coverage is not necessarily equal across the country. For example, both the RHMs currently working in Macedonia are working in the largest Roma community. They are therefore expected to serve only Roma living in that community—not Roma living elsewhere in Macedonia.

Nonetheless, the numbers show: (1) there is enormous variation in the number of RHMs per Roma inhabitant, and (2) there are relatively few RHMs relative to the need in all 6 countries. Bulgaria and Romania have the greatest coverage, and Slovakia and Ukraine have the poorest coverage.

TABLE 1: Number of RHMs per country

Country	Roma population*	Number of RHMs	Ratio
Bulgaria	750,000	105 (budget for 130 for 2012)	1.35 RHMs per 10,000 Roma (1.73 per 10,000 in 2012)
Macedonia	197,750	16 (planned for 2011) 2 currently working	currently 0.1 RHM per 10,000 Roma (0.81 per 10,000 planned for 2011 and 1.62 per 10,000 planned for 2012)
Romania	1,850,000	380	2.05 RHMs per 10,000 Roma
Serbia	600,000	75	1.25 RHMs per 10,000 Roma
Slovakia	500,000	30	0.60 RHM per 10,000 Roma
Ukraine	260,000	14	0.54 RHM per 10,000 Roma

<sup>\*</sup> Source: European Commission (2011). Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. COM(2011) 173 final.

TABLE 2: Gender of the RHMs

Country	RHM gender		
Bulgaria	Preference given to women—currently about 70% female		
Macedonia	Preference will be given to women		
Romania	100% female (1 man)		
Serbia	100% female		
Slovakia	About 60% female		
Ukraine	About 60% female		

#### 5.3 Issues to Consider in Designing Mediator Programs

► Gender of the RHMs. Some countries employ only female Roma Health Mediators, others employ both males and females.

Many RHM programs give preference to women because they are seeking to empower Roma women through Roma Health Mediator training and employment. Employed Roma women can serve as role models for other women in their communities. There are other reasons to select female Roma Health Mediators. In some contexts, only female RHMs can discuss health concerns with female clients. Moreover, since in many communities, women take primary responsibility for the health of children and other family members, having female RHMs means that women and their families can be reached with mediator services. Women are not prohibited from advising men, in many communities, it can be acceptable for female RHMs to educate men about certain health topics. Finally, most applicants for RHM positions are female, so it might be difficult to find enough qualified male candidates.

However, insofar as RHM programs seek to address sexual and reproductive health and domestic violence, engaging men is essential. Evidence from many countries in the world (both developing and developed countries) shows that educating men about reproductive health issues and about gender equality is required to affect change, as men hold decision-making power in many of these areas.<sup>44</sup> Educating women may be insufficient, as they lack the power to make choices about contraception or to end domestic violence in their communities. Program planners may want to consider hiring male mediators to fill this role or otherwise ensure that other NGO or governmental programs are reaching men. A small Roma NGO in Kosice, Slovakia, for example, conducts group activities with adolescent boys to improve their health behaviors and change their norms about gender roles.<sup>45</sup>

Human rights/anti-discrimination mandate of the RHMs. In general, RHMs have some human rights training, but they have little mandate to address rights violations beyond helping to ensure that individual clients are not over-charged for services and referring clients who may have experienced violations to NGOs or government anti-discrimination bodies. For example, Bulgarian RHMs are very knowledgeable about patients' rights standards in Bulgaria and the prices for different kinds of care, and they report assisting numerous clients with filing complaints in instances of abuse. Some interviewees stated that it would be better for Roma Health Mediators to have a more explicit human rights mandate. However, program planners need to be cognizant of the RHMs' role in the community and in the public health system. While RHMs can and should advocate for their clients, they should not be positioned in an adversarial way to providers and the

health system. To be sure, rights advocacy is important, and this role should be taken up by NGOs and other entities.

To what extent do RHMs assist the health system and to what extent are they community organizers? Even within countries, practice varies. Country reports suggest that some RHMs in Romania and Serbia may spend most of their days based in a health facility, where they work with Roma clients as they enter. Other RHMs in these countries spend most of their day in the community, working with individual clients and conducting health education sessions. Still others may be organizing community members for events such as health campaigns or advocating for the presence of particular types of health providers in local health centers. Since they are tasked with mediation, Roma Health Mediators can be most effective if they spend time in communities and at the health facility.

Roma Health Mediator activities vary in part because many programs are decentralized; RHM responsibilities are determined at the municipal or county level, rather than the national level. Moreover, RHMs based in urban areas are more likely to spend time in health care facilities or offices, as the target population is close by. In rural areas, they are more likely to spend time travelling and visiting villages.

There are advantages and disadvantages to each approach. Roma Health Mediators sitting in health facilities may develop strong relationships with providers, and improve provider knowledge and empathy for Roma clients. RHMs working largely in the community may bring optimism to communities about what Roma living in ghettoized settlements can achieve. The best role for Roma Health Mediators depends in part on the presence of other personnel and programs. Some countries, namely Macedonia, Serbia, and Slovakia, have visiting (so-called patronage) nurses or community nurses, who can work both in health facilities and Roma communities. RHMs should complement, rather than replicate their role. Communities with strong Roma NGOs may be less in need of community organizers. The presence of other services and advocates should be considered in developing local work-plans for mediators. Similarly, Roma community members should be provided the opportunity to express their preferences regarding how and where mediators work.

Who will supervise RHMs? In some countries, NGOs initially supervised RHMs, and responsibility later passed to health officials or to local authorities. In other countries, health officials or local authorities have supervised RHMs from the program's inception. Again, there are advantages and disadvantages to each scenario. Having local authorities or the health system supervise Roma Health Mediators ensures that RHMs are part of the governmental system. In some cases, however, RHMs report that they in fact have little to no contact with the public sector individuals mandated to supervise them. NGOs may be particularly suited to provide initial supervision, when RHMs might be in need of extra support, or when programs are still being developed and adapted to function optimally. If the local government or health system is truly committed to supporting mediation, partnerships between NGOs might be ideal. In this case, the NGO could build governmental capacity to supervise mediators and to work in Roma communities. At the same time, RHMs remain firmly ensconced in the public system. Regardless of who supervises RHMs, regular, supportive supervision is essential.

# 6. Roma Health Mediation Successes<sup>46</sup>

Many of the benefits of Roma Health Mediator programs cannot be measured. Indeed, recent contributions to the cost effectiveness literature note that assigning a monetary value to activities and their health impacts is insufficient to capture all effected changes.<sup>47</sup> Health programs have the potential to: I) directly affect health, and 2) change the nature of the community in which the program occurs. In some cases, this second outcome can be even more significant in the long run than direct health improvements. Moreover, hierarchical health programs that focus only on improving health indicators can have an overall negative effect, as they perpetuate exclusion and disempowerment. For this reason, health economists and policymakers have started to assess measures related to community transformation in their cost benefit analyses. These measures might include community involvement in health and policymaking, social cohesion, and rights knowledge and empowerment.<sup>48</sup>

In the case of Roma health mediation, evidence suggests that mediators both directly affect health and change the nature of the community in which programs occur, at a relatively small cost. See Annex 3 for a table showing the costs and benefits of RHM programs. Respondents to a survey on the Decade of Roma Inclusion in Bulgaria, Macedonia, and Romania gave relatively high marks to government activities to improve Roma women's health. These positive responses may be due to the existence of Roma Health Mediator programs.<sup>49</sup>

The following two sections outline the tangible (would be measured by a traditional cost benefit analysis) and less tangible benefits (would not be captured by a traditional cost benefit analysis) of RHM programs. The degree of the benefit depends on the duration, sustainability, and quality of the program activities.

#### 6.1 Tangible Benefits

The qualitative review shows that mediators in all countries studied are generally successful in providing the following services:

**Vaccination.** Many isolated Roma communities lack adequate access to health care, and as a result, are disproportionately unvaccinated. Moreover, in some communities, Roma community members reportedly distrust and/or fear vaccination, leading to even lower rates of vaccination A survey carried out by UNICEF in Macedonia found that only 66% of Roma children were fully vaccinated, as opposed to 76% of the population overall.<sup>59</sup> Of the Roma respondents to a UNDP survey in Southeastern Europe, 15% of Roma children under age 14 were not vaccinated, in comparison to 4% of the non-Roma children.<sup>51</sup> There have also been reports of measles outbreaks in Roma communities; measles is a vaccine preventable disease. For example, the WHO investigated a measles outbreak in Romania and discovered that 90% of the reported 6,000 infected were Roma.<sup>52</sup> Measles outbreaks in Roma settlements have also occurred in Germany, Greece, Italy, Poland, Portugal, and Serbia.<sup>53</sup>

Increasing vaccination rates among the Roma is a widely shared priority; both Roma NGO representatives and governmental representatives interviewed as part of the review pointed to vaccination as a key concern. In some contexts, RHMs work with family doctors to locate Roma who have not shown up for a scheduled vaccination. In other contexts, RHMs support Ministry of Health vaccination campaigns by cooperating with health care workers who are trying to vaccinate large numbers of children in Roma settlements. For example, the National Network for Health Mediators in Bulgaria (the Bulgarian professional association of RHMs) reports that in 2010, Bulgarian RHMs assisted in the emergency vaccination of 188,703 children following a measles outbreak in a Roma community. Roma Health Mediators may also incorporate vaccination into their regular health education work, and inform pregnant or new mothers about the importance of vaccination. Because governments do not keep disaggregated data regarding vaccination rates and because unvaccinated children are often also undocumented children, we do not know how much RHMs have improved vaccination rates among the Roma. However, public health authorities and doctors often describe vaccination as a key success of the Roma health mediation program. Doctors and nurses can certainly observe if more Roma are being vaccinated.

RHMs in Slovakia did not work between January and March of 2011 due to difficulties in allocating funding. During their contract break, physicians contacted the local offices of public health to ask for help in locating Roma who had not reported for a scheduled vaccination, attesting to the fact that doctors rely on RHMs for this assistance.<sup>54</sup>

However, it is important to note that Roma health mediation should only be a short term solution to ensuring that all Roma children are vaccinated. Roma health mediation can help promote access to the health system, but activities such as vaccination campaigns in Roma settlements are not long term solutions. Bringing health services to Roma communities can address urgent needs, but such activities do not end the need for functioning, accessible, affordable health care. Over the long-term, Ministries of Health should work to ensure that Roma are vaccinated at the scheduled times, and that vaccine campaigns are not required.

Helping clients to obtain documents and insurance. As noted, Roma throughout Eastern Europe may lack the birth certificate, ID card, or residential registration required to access essential services, including social protection and health insurance.

RHMs assist clients with obtaining documents and health insurance coverage by helping them to complete forms and accompanying them to relevant offices. Roma Health Mediators are usually well-versed in the regulations and requirements for obtaining documents and insurance (although they require continuing education to keep up-to-date on changing regulations). Some RHMs proactively search for people in the community who may lack documents or insurance. So, for example, Roma Health Mediators in Bulgaria report that they search for women who have recently given birth to ensure that the mothers have the required documents to receive the appropriate benefits.

RHMs keep data regarding the number of persons they assist in obtaining documents and insurance. However, unfortunately, some countries, including Romania, do not aggregate this data on the national level; data is merely collected and analyzed by the local level authorities supervising mediators. Moreover, the data is not always easy to interpret. In some cases, it is hard to know if the data refer to the number of clients who are advised about what to do. or if the data describe the number of people who successfully obtain documents. Nonetheless, the numbers are impressive. For example, in Ukraine, 14 RHMs working from 2010 to March 2011 helped 986 Roma get registered and assisted another 413 to obtain passports. In Serbia, in the period between April 2008 to December 2010, 75 RHMs facilitated the issuance of identity papers and health insurance cards for 9086 clients. From 2008 to 2009, 67 Bulgarian RHMs helped 2,079 individuals obtain health insurance. This assistance undoubtedly results in concrete improvements in RHM clients' lives; as a result of the Roma health mediation program, individuals now have the right to access free health care and other services.

However, as with mediator successes related to vaccination, the successes of RHMs in increasing the number of Roma who have documents and health insurance should be qualified by a few caveats. It is important that the legislative framework of each country enables access to documents for all who are entitled. Official or unofficial fees and complex bureaucratic procedures make it harder for all poor and/or poorly educated people to obtain documents. These laws should be changed; it should not be the task of RHMs to help clients to navigate unreasonable systems. Some countries have recently changed their legislation. As reported by interviewees in Serbia, for example, the government has recently eased documentation requirements, allowing Roma to obtain health cards based on the statement of two witnesses regarding their residence. Macedonia, too, has recently changed their health insurance law to allow coverage based on Macedonian citizenship, rather than employment status, as it had been. Five thousand persons have applied for health insurance under this new law.<sup>55</sup> However, as noted, between five and ten thousand "habitual residents," many of whom were born in regions of the former Yugoslavia that are now independent countries, lack citizenship, making it very difficult for them to obtain health insurance.<sup>56</sup>

Health education. As noted, there is no way to measure the impact of health education on health status in Roma communities. However, governmental and nongovernmental interviewees, as well as Roma Health Mediators themselves, felt health education was an area where mediators had impact. They explain that health education has contributed to increased use of preventive care within Roma communities. Moreover, in cases where health education has included information about social and health care entitlements, the benefits can be great. RHMs sometimes include information about what health care services should be provided free of charge and other such information in their health education sessions. Clients sometimes avoid going to the doctor because they believe they will be charged money; learning that certain services can be free removes another barrier to health care utilization.

RHMs may spend a substantial amount of time on this task. For example, Roma Health Mediators in Bulgaria reported holding 1,194 health education sessions over the course of a year.<sup>57</sup> During these sessions and individual consultations, RHMs distributed 28,641 health brochures. However, health education materials are not always appropriate. For example, the health education materials in Slovakia were text heavy, making them difficult to understand for those who had trouble reading or who could not read at all.

Accompanying Roma to the doctor. The need for mediation between some Roma patients and doctors is one of the initial justifications for RHM programs. RHMs successfully complete this task in all countries included in the review. In focus groups and in questionnaire responses, RHMs reported that they:

- Provide linguistic translation for Roma who speak only Romanes
- Translate physician instructions into easy to understand language
- Help Roma who are uncomfortable to feel less intimidated in a health care setting

- Note instructions given by physicians and follow up with patients to make sure that they are correctly following the instructions
- Help physicians better understand Roma concerns

The current review did not include surveys of Roma Health Mediator clients. However, the 2005 review did, and clients were universally positive in their appraisal of Roma Health Mediators' accompanying them to the doctor. Recent videos from Macedonia and Serbia show clients speaking positively about the assistance they received from RHMs.<sup>58</sup>

Changing health care provider knowledge and attitudes. The need for RHMs to accompany Roma clients to the doctor should decrease over time. After having interacted with many Roma patients and RHMs, doctors will become more competent in serving Roma patients, and Roma patients will become more comfortable with going to the doctor. This process has already started among health care providers who have worked with RHMs. NGO representatives interviewed in Ukraine reported that doctors were more willing to serve Roma patients as a result of having worked with RHMs. Roma Health Mediators in Slovakia explained that in the four years since they started working, their level of cooperation and mutual understanding with doctors have increased substantially. Doctors are not only respectful of the RHMs' role, but they are more competent and professionally committed to working with the Roma community. Moreover, RHMs report that doctors with whom they work are much less likely to engage in discriminatory behavior and to use abusive language now than they were at the beginning of the Roma Health Mediator program.

Some physicians reportedly refuse to serve Roma patients, but those who do work with Roma patients likely become better doctors as a result of working with RHMs. In other words, as a result of working with Roma Health Mediators, doctors better understand how to address Roma and other excluded clients. After working with RHMs and Roma clients, physicians may provide better quality of care and enjoy more effective interactions with Roma patients even if Roma Health Mediators are not present.

**Increased access to other services.** RHMs help clients to access other services through 3 routes: 1) increasing access to documentation, 2) referral to other public services, and, 3) informal mechanisms, such as ensuring that Roma benefit from humanitarian aid distributions.

As explained, RHMs in many countries assist Roma in obtaining national identity documents. These documents can be a prerequisite for obtaining health care as well as social protection services (child allowances, unemployment benefits, maternity benefits, and so on). Roma Health Mediators also refer clients to educational, social, and other services. For example, a RHM in Serbia reported that she had assisted a child with disabilities to enroll in a school for children with disabilities. The child had been staying at home before the referral.<sup>59</sup> Serbian

RHMs also reported that they had cooperated with humanitarian projects conducted by international NGOs and others, ensuring that the most needy Roma benefit.<sup>60</sup>

#### 6.2 Less Tangible Impact of RHM Programs

Increased number of employed Roma in settlements with persistent unemployment. Some of the most isolated Roma settlements have unemployment rates as high as 100%. Roma who *are* employed often have low quality jobs that are characterized by low salaries and high turnover rates. Economists have concluded that such high rates of unemployment are due to low education levels as well as discrimination. Unemployed Roma are often described as "discouraged workers," they have long ago stopped seeking employment because they have been repeatedly unsuccessful. In this context, having a trained Roma professional working in the community can improve community morale, and serve as an example to others. RHMs are visible as members of the community who perform tasks the community appreciates. Moreover, they are trained and generally respected by local health providers and municipal authorities, demonstrating to the most excluded Roma communities that quality employment is possible. This is particularly the case in countries where mediators are required to have finished only primary school. Community members can identify with RHMs and imagine themselves in that position.

Ensuring the RHMs are sustainably employed is essential to maintaining this morale-boosting aspect of Roma health mediation. Contract breaks, low salaries, and other interruptions erode community trust in mediators and show that mediators are not well respected by the governments.

Trust in health services increased. Among other reasons, health care utilization among the Roma may be low because Roma do not trust the health system. After having consulted a medical professional in the presence of an RHM, clients may feel more confident that they can receive quality care. They may tell their family and neighbors about their positive experience. RHMs who work consistently in the same communities for a long period of time report that community trust in the health care system increases.

Here too, long-term, consistent presence by the RHMs is essential to fostering and maintaining this change.

Career prospects of Roma RHMs improved. Most programs do not keep track of this data, but anecdotal evidence suggests that RHMs have pursued additional training for personal and professional enrichment, as well as career advancement. For example, a survey of RHMs in Romania revealed that 10% of them had furthered their training since becoming a Roma Health Mediator. In Bulgaria, 15 RHMs are currently in school or have finished their Bachelors'

Degree, and 3 have completed a Master's Degree. Some have pursued nursing or social work degrees with the support of OSF and other scholarship programs. Career advancement is good for the RHMs involved, but it also advances the cause of Roma empowerment and inclusion. As noted, Roma exclusion from the labor market is extensive. RHMs constitute a cadre of trained professionals, some of whom go on to join professional cadres that require even further training. Increasing the number of Roma social workers, nurses, and physicians will also erode anti-Roma sentiment and stereotypes within these professions and improve quality of care. For example, representatives of the Association of American Medical Colleges, the organization of medical schools in the United States, argues that racial diversity in the health care workforce leads to higher quality of care for minority patients and the formulation of superior public health policies.65

RHMs act as community resources. In focus groups, many RHMs noted that they provide important services beyond their mandate. These include helping people to understand and respond to official documents and mail, providing mediation in the school setting (in countries without education mediators), and supporting/encouraging adolescents to continue their schooling. However, it is important to note that in many cases, RHMs are tasked with too many activities that are beyond their job description; they are over-burdened because there are too few RHMs, and too few (if any at all) social workers and patronage nurses working in Roma communities.

# 7. Roma Health Mediation Challenges

Several challenges limit the effectiveness of Roma health mediation programs. Challenges can be grouped into two categories: (I) Challenges linked to the structure and operation of RHM programs. These challenges can be addressed by changing the program. (2) Challenges beyond the mandate of Roma health mediation. For example, factors such as persistent poverty limit RHM effectiveness. These challenges must be addressed through other public policies; Roma health mediation can only address them in a very limited way.

# 7.1 Challenges Linked to the Structure and Operation of RHM Programs

Low salaries for Roma Health Mediators. As shown in Table 3, salaries for RHMs vary enormously. Variation is due in part to differences in the cost of living; costs are higher in countries that belong to the European Union, for example. In some countries, RHM salaries compare somewhat poorly to other salaries. The salaries of RHMs in Slovakia have not changed since the inception of the program (2005). In contrast, Macedonia has set the Roma Health Mediator salary at the same level as all other health sector salaries that require an equivalent level of

education. It is also important to note that in several countries salaries for health care workers in the public sector overall may be lower than the average national salary.

Low salaries are even more deficient when RHMs do not receive adequate resources (financial or otherwise) required to complete their jobs. These RHMs are forced to use earnings from their salary to pay for transport, phone and SMS use, and other job-related costs. Roma Health Mediators in Romania, for example, report that they are not reimbursed for travel and communication costs and for paper and other supplies. Some RHMs in Serbia are given free bus tickets by the local government, and others are not. Similarly, some municipalities provide RHMs with a small budget for travel and telephone, and others do not.

Country	RHM salary and support for expenses	Contract type
Bulgaria	153 to 200 Euros (depending on the municipality; the average is about 165)	Annual. Had been substantial problems with budget allocations every year, but these appear to have been solved.
Macedonia	About 305 Euros (the MoH has also created a budget line to cover the cost of preventive home visits)	Not yet determined
Romania	About 133 Euros	Annual contracts for about 70% of the RHMs (remainder have open-ended contracts). Increasing problems with failure to renew due to financial crisis. Recent salary cut for all RHMs, and increasing problems with payments not made on time.
Serbia	170 Euros	Project-based, although almost all RHMs are on a contract that must be renewed every 3 months. Some problems with payments not made on time.
Slovakia	365 Euro (498 Euro for the Mediator Coordinator) (33 Euros/month for materials)	Annual contract, with no funding secured for post 2015. Persistent problems with allocating funding when contracts are renewed each year, leading to salary delays or periods without salary/employment.
Ukraine	212 Euros (89 Euros/month for expenses)	Project-based contract currently until December 2012.

Low salaries and funding for other activities undermine RHM morale and suggest that the government (or whomever is paying the salary) does not value Roma Health Mediator expertise and work. Lack of consistent contract (either because the contract must be renewed every 3 months or annually or because the contract is contingent on short-term program funding) further erodes morale.

Inadequate supervision. The quality and extent of supervision varies among and within countries. To be sure, many RHMs receive regular, supportive supervision. However, too many do not. Academics and public health implementers have amply demonstrated that supervision is one of the most important determinants of success of programs such as Roma health mediation.66 Roma health mediation and other program planners may fail to allocate sufficient funding to supervision, or they may not understand how much time should be devoted to this task.<sup>67</sup> Poor supervision contributes to low morale and decreased mediator effectiveness. Mediators who do not receive enough supervision may not have a chance to request materials or other required support, they may not learn how to address certain problems their clients experience, and they may not learn about relevant changes to the health and social systems in their country. Although providing adequate supervision costs money, this investment is essential to ensure that the investment in Roma Health Mediator training and salaries pays off.

### **Supportive Supervision**

In contrast to traditional supervision, supportive supervision involves more than a hierarchical approach to ensuring that employees are performing the basic tasks of their job. Supportive supervisors communicate objectives, monitor progress and provide feedback, ensure that employees have the resources required to do their job, help employees to solve problems, ensure that employees have access to professional development and enrichment, and motivate and support employees to improve performance (Berdzuli et al., 2008). Many mediators do not receive supportive supervision. Lack of supportive supervision negatively impacts RHM effectiveness and professional development.

In the case of RHMs, supervision can be inadequate because of national level program weaknesses or because of local level implementation challenges. For example, Slovakia and Bulgaria did not adequately provide for supervision in their national level planning. Slovakia did not allocate any additional funds to local Offices of Public Health to supervise or support RHMs, although RHMs are mandated to be present in these offices one day per week. Some Offices of Public Health have allocated staff time and other resources to ensuring mediator supervision, but other offices have not. Similarly, Bulgaria did not name a national level point person for Roma health mediation until May 2011, undermining national level planning for supervision and program activities. Lack of a national level leader also makes program monitoring and adaptation difficult.

In other cases, poorly planned or implemented decentralization processes have left RHMs with inappropriate supervision in some locales. Supervision for Roma health mediation was decentralized in Romania in 2009. Under the newly decentralized system, RHMs were to report to local family doctors. However, some RHMs work with multiple family doctors who give them too much work, over-burdening RHMs and preventing them from continuing with their normal community building activities. In some cases, family doctors do not provide the supervision required, and the mayor or representatives of social services intervene and tell RHMs what to do. In other cases, supervision is of good quality.

Finally, RHMs and other interviewees in many contexts noted that RHMs do not benefit from supportive supervision. In other words, rather than having an opportunity to share and address challenges or to learn more, supervision can be a way for supervisors to "tell Roma Health Mediators what to do" and to collect data about Roma Health Mediator activities. Top down, as opposed to supportive, supervision represents a missed opportunity to enhance Roma Health Mediator capacity and self-confidence.

Lack of professional development opportunities. Professional development could include continuing education for professional enrichment, as well as formal opportunities for job advancement. Some RHMs lack both. Roma Health Mediators expressed a strong desire for additional training in focus groups.

The Council of Europe trainings and the Open Society Foundation Roma Health Scholarship Program (in Bulgaria, Macedonia, Romania, and Serbia) provide opportunities to mediators in several countries. However, not all Roma Health Mediators will have access to these programs. Moreover, some RHMs have been devoid of training for several years. Roma Health Mediators in Slovakia, for example, were trained in 2005. Those hired since then have only received training by their supervisors at the local Office of Public Health. RHM professional associations also facilitate professional development, as RHMs share and learn from one another and host events such as guest speakers. The Bulgarian National Network of Health Mediators and the newly established Roma Health Mediator association in Romania both have regular meetings. Serbia convened all RHMs for an information sharing event in 2009. UNI-CEF has also planned a training and additional support for RHMs to address early childhood development in Southern Serbia.

### **Community Health Workers**

"Community health workers" refers to a cadre of community members who have been trained to provide health services throughout the developing world. Some community health workers provide health education, make referrals, and support vaccination campaigns, similar to the work mediators undertake. Other community health workers provide direct medical care. Because most community health workers are based in rural communities in the developing world, their working context is quite different from RHMs'. However, there is vast public health literature reviewing community health worker programs. This literature might be helpful to RHM program planners. Lack of supervision and continuing education are frequently cited as challenges, similar to RHM programs. The US Agency for International Development (USAID) recently launched a website, "CHW Central," which provides tools and other resources for community health work. Many of the tools are appropriate for health workers with less than a high school education, which is relevant to mediators in some countries. See: http://www.hciproject.org/ chw-central. Finally, there are community health workers addressing under-served communities in Europe and the United States. The U.S. Centers for Disease Control has compiled a database of reports and information regarding the successes and challenges of these programs. See: http://www.cdc.gov/diabetes/projects/ comm.htm#2.

Governments fail to leverage RHM experience. Roma Health Mediators have accumulated experience and expertise in the challenges to improved Roma health. Despite this, governments may fail to use RHMs' expertise as a resource for other programs. For example, in Slovakia, Roma Health Mediators rarely share their experiences with Office of Public Health staff. Isolated RHMs in Romania may interact only with the local family doctor who supervises them.

Failure to learn from RHM experience and to involve them in program planning represents a lost opportunity to improve other programs. It is also a missed chance to boost mediator morale and sense of professional accomplishment.

Persistence of a hierarchical approach to Roma health that focuses on health care and not on the social determinants of Roma health. This challenge is partly due to the fact that public health is still a developing field in several countries included in this review. Governmental health activities are primarily oriented toward delivering services, surveillance, and didactic health education, rather than taking a participatory, community-building approach to health promotion. Hierarchical approaches may also be related to widely held stereotypes about Roma and lack of recognition that discrimination plays a role in shaping Roma health. Some governmental representatives may treat Roma health as a problem stemming primarily from bad habits and entrenched poverty within the Roma community. This approach has implications for the design and implementation of Roma Health Mediator programs. The current program in Ukraine, for example, appears to be oriented toward RHMs' educating Roma community members about hygiene, and distributing didactic health education materials. Roma Health Mediators too, may adopt this hierarchical approach. In Serbia, several people reported that RHMs are supervised in a very strict hierarchical manner, and some RHMs in turn treat their clients in this way. The outcomes of such Roma Health Mediator programs are compromised. RHMs are less able to facilitate the community transformation described earlier. Instead, especially punitive approaches can perpetuate exclusion by suggesting that Roma Health Mediators and clients are not capable of setting priorities, making good choices, and of working together to improve their communities.

### **Health Promotion**

Health promotion is defined in WHO's Ottawa Charter as: "the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment" (WHO, 1986). Mediators then, should be working with communities and the health system so that excluded Roma may achieve this. This community building and empowerment approach is echoed in the European health equity frameworks noted earlier. The EU health strategy, for example, emphasizes the importance of citizen empowerment and the human right to access health care (Commission of the European Communities, 2007).

Insufficient cooperation with other actors in the health care system. In some regions of the countries with established Roma Health Mediator programs—Bulgaria, Romania, and Serbia—Roma health mediation programs do not promote collaboration with related professionals. Few RHMs reported cooperating with visiting (patronage) or community nurses or with educational mediators. RHMs in Serbia, however, reported conducting joint visits with visiting nurses.

Including complementary professionals in official mediator job descriptions and in some portion of mediator trainings and events might facilitate cooperation. Cooperation promotes more efficient and effective service provision, and helps to build the capacity of other service providers to work in Roma communities. The trainings provided by the Council of Europe, for example, will include local officials and service providers, as appropriate.

Decentralization. Decentralization is not inherently negative. However, too often, decentralization means uneven support for Roma health mediation. As noted, the quality of supervision in Romania varies according to the interest and capacity of different municipalities. Moreover, prior to decentralization, national level authorities should develop clear and basic standards for Roma Health Mediator work and supervision. In Romania, this did not occur. Similarly, in Serbia, some municipalities are more supportive than others. For example, some municipalities provide tickets for transport so that Roma Health Mediators can reach rural settlements; others do not.

It is likely that the most poor and most needy municipalities are also the ones that are less able to supervise and manage mediators. The national level project manager for Roma Health Mediation (where this position exists) should ensure that RHMs working in areas where need is greatest do not receive the least amount of support.

Contract insecurity or problems with budget allocation. Some RHM programs, Bulgaria, Serbia, and Slovakia in particular, have been plagued by inconsistent financing and/or contracts. RHMs may work without pay—or not work at all—at the beginning of each calendar year as contracts and pay are finalized. In the case of both Bulgaria and Slovakia, this period often lasts 3 months. In Serbia, RHMs must get their contract renewed every 3 months. Interviewees suggested that failure to ensure contracts and salaries is due to inadequate commitment within the government, as well as difficulties inherent in creating new public sector cadres. Mediation is an officially registered profession in Bulgaria. The government has added few such professions, and the process is complex, particularly given the parallel processes of EU-accession related reforms. However, in the case of Bulgaria, it appears that the problem of contract insecurity has been definitively resolved, following persistent national and international advocacy by the NGOs and other stakeholders involved. In Serbia, most Ministry of Health contracts require monthly renewal, including RHMs. However, the Ministry recently revised the term of RHM contracts from 1 to 3 months.

Insecure employment is bad for RHMs and bad for their work. RHMs feel under-valued, contributing to poor morale. Moreover, their role in the community is compromised, as they are unable to respond to requests for assistance when they are not officially working. As noted, RHMs also serve as an example of progress and inclusion in the most isolated communities. Their being predictably unemployed 3 months of the year indicates that the government is not in fact committed to inclusion.

Physicians rely on RHMs to aid Roma clients, relieving themselves of this responsibility. Sometimes, health providers rely on RHMs too much. RHMs reported in focus groups that physicians sometimes asked them to explain things to the patient, rather than the doctor trying to do so. There were isolated reports of RHMs going to social service or doctor appointments without the client. Roma health mediation should build health provider and client capacity to communicate with one another—not replace this communication. Better training for RHMs on how to facilitate patient/doctor communication might help to lessen this problem, as might including doctors and other health providers in some of the trainings for RHMs.

### 7.2 Challenges Beyond the Mandate of Roma Health Mediation

**Poverty.** Poverty negatively impacts the health status and health care access of all of the poor. Roma are particularly affected as they are disproportionately poor. Some patients are unable to pay for the transport to health care or to pay for medicines prescribed. RHMs cannot address this problem. Indeed, RHMs surveyed for the 2005 review as well as the current review reported encountering patients who could not pay for medicines or return visits to the doctor as one of the challenges they encountered most frequently.

Governmental and nongovernmental interviewees confirmed this challenge. Studies also show that poverty limits health seeking behavior. For example, in a survey conducted among Roma and poor ethnic Romanians in Romania, only 68% of the Roma said they would go to the doctor after coughing for three weeks, compared with 99% of the ethnic Romanians. Forty seven percent of the Roma said they would not go because of concerns about cost, as compared to 22% of the ethnic Romanians. <sup>68</sup>

The global financial crisis has deepened poverty for some Roma, and in some cases, governments have made policy choices that further limit their ability to address poverty. In 2009, the WHO European Region urged Member States to ensure that their health systems continued to address the needs of the most poor and vulnerable in the face of the financial crisis. <sup>69</sup> Nonetheless, countries are making cuts. For example, Slovakia has eliminated its community nursing program and has decreased the number of social workers. Romania has cut the amount of funds given to foster parents to support foster children. <sup>70</sup> Some Bulgarian RHMs have had their contracts cut to part time due to lack of funds to pay them. Romania has imposed a salary freeze on RHMs, and some municipalities have opted not to renew mediator contracts.

Roma are sometimes ignored in larger health strategies. As noted, "aiming for the mainstream" is one of the 10 common basic principles of the EU Roma Platform. Roma health mediation is one effective targeted program to improve Roma health, but Roma health mediation must be complemented by other programs.

While Decade Action Plans or other national Roma strategies may call for mainstreaming Roma health concerns, national strategies for tobacco control, maternal and child health, reproductive health and so on may lack Roma-specific components. For example, Serbia's strategies for Youth Development and Health and for National Mental Health Protection do not mention any particular measures or approaches for the Roma.<sup>71</sup>

When questioned about why there are no activities specifically addressing the Roma, such as Romanes-language radio or television campaigns, Ministry of Health representatives often respond that their national strategies treat everyone the same, and that all residents have equal rights to access health and social care. However, treating everyone the same by having the same strategy for all groups is inconsistent with an equity approach. Health systems promote health equity when their design and management specifically consider the circumstances and needs of socially disadvantaged and marginalized populations.72 Mainstream strategies may need to incorporate specific measures to reach all groups, including the Roma.

# 8. Roma Health Mediation Country Reports

The following sections provide a brief overview of Roma health mediation in each country. See Annex 2 for a more detailed description of RHM training in each country.

### 8.1 Bulgaria

Roma health mediation began in Bulgaria in 2001 as a pilot project of the Ethnic Minorities Health Problems Foundation (EMHPF), a Bulgarian NGO. From 2003 to 2007, PHARE assistance allowed a consortium of agencies—EMHPF, Bulgarian National Council for Cooperation on Ethnic and Integration Issues (NCCEII), Bulgarian Family Planning Association, and the Open Society Foundation-Bulgaria—to scale up the project.<sup>73</sup> RHMs participated in a basic training when they started, and then benefited from trainings in additional topics every year.

2007 was an important year for institutionalizing the Roma Health Mediator program in Bulgaria. In 2007, the Ministry of Health and the Bulgarian National Council of Ethnic and Demographic Issues approved the RHM curriculum developed by EMHPF, the Bulgarian Family Planning Association, Open Society Foundation-Bulgaria, and the CEEN Consortium.<sup>74</sup> The Medical College in Plovdiv became the official training host and certification provider.

Moreover, the government added Roma health mediation to the National Classification of Professions. The program also became more financially sustainable in 2007, when funding for RHM salaries was delegated from the Ministry of Finance. Finally, supervisory responsibility passed from the EMHPF to municipal authorities. Exactly which municipal authority supervises mediators varies; it is often the chief of the municipal public health department or the mayor. RHMs provide monthly reports to their supervisors.

The National Network of Health Mediators was founded in 2007 as well, though the government does not provide funds for this network. The network is comprised of over 80 RHMs, doctors, nurses, RHM trainers, and experts in public health and social exclusion. The frequency of meetings and professional development activities depends on the funding available, and at present the association is funded by outside donors, such as OSF. Moreover, the Network is increasingly involved in RHM supervision, cooperating with municipal authorities to undertake this task. In 2011, the government nominated a Ministry of Health focal point to provide national level coordination to Roma health mediation. The focal point and the Network work together to collect and collate national level data regarding RHM activities. However, the Network's work is limited by the need to raise funds for all activities. Since 2007, RHMs have not benefited from any national-level continuing education, with the exception of the Council of Europe mediator training project. However, many RHMs have benefited from multiple local trainings led by international and national NGOs and others. Some are regularly invited to participate in planning and strategy meetings that are relevant to their area of work.

In 2011, there are 105 Roma Health Mediators working, with a budget for 130 RHMs to work in 2012.

Overall, Bulgaria's Roma Health Mediator program is well-institutionalized compared to programs in many other countries. The program is managed by the government, financially sustainable, and included in the official list of professions. Moreover, the consistent and dedicated involvement of EMHPF, the Bulgarian Family Planning Association, and the Open Society Foundation-Bulgaria has ensured strong advocacy for the program. These agencies were also able to offer different types of expertise. The Bulgarian Family Planning Association is the national affiliate of the International Planned Parenthood Federation (IPPF), and as such, has strong connections to IPPF affiliates in neighboring countries. Indeed, Bulgarian program planners have served as a resource for programs in other countries. In 2010, with financial support from the Open Society Foundations, Bulgarian RHMs along with representatives of the Bulgarian Family Planning Association and EMHPF went to the neighboring country of Macedonia to share their experiences with Macedonian governmental and nongovernmental agencies. In the fall of 2010, the Bulgarian Family Planning Association organized a study trip for Macedonian officials to see the program in Bulgaria. Similarly, RHMs trained by CARE International and working in Southern Serbia undertook a study visit to Bulgaria, where they met with Bulgarian RHMs, local authorities, health care providers, and government officials. The visit was organized by the Bulgarian Family Planning Association.

The recommendations below suggest ways of addressing ongoing challenges.

- Identify a national level Roma Health Mediation project manager within the Ministry of I. Health. Such a person could help to gather data to show the efficacy of RHMs, ensure more consistent supervision at the municipal level, and ensure continued and adequate budget allocations to prevent any future employment interruptions. Bulgaria's Health Strategy for Disadvantaged Populations Belonging to Ethnic Minorities includes the objective of firmly establishing the Roma Health Mediator position. Naming a project manager within the MoH would help the government achieve this objective.
- Increase the number of Roma Health Mediators, so that their number corresponds to 2.. the actual need of the Roma population.
- Allocate governmental funding for continuing education and for the functioning of 3. the national Network of Health Mediators. The government should also recognize the national professional association, elevating them to the same status as other networks of health professionals.
- Ensure the continued monitoring of RHMs through the established Network of Health 4. Mediators.

### 8.2 Macedonia

The RHM program in Macedonia is comparatively new; it was included in Macedonia's 2009-2012 Decade Health Action Plan. With support from the Open Society Foundations, the Macedonian NGO HERA, a sexual and reproductive health organization, has already trained and currently supervises two RHMs who work in a health care center in the largest Roma community in Macedonia, Shuto Orizari. HERA is spearheading the RHM program expansion. To build political commitment and to ensure institutionalization of the program, HERA convened a working group comprised of relevant ministries, NGOs with experience in Roma health, and WHO. This group prepared a strategic framework for Roma Health Mediation that the Ministry of Health successfully presented to the government for approval.

The government has allocated some funds from the MoH preventive health program budget to support mediation. Moreover, following successful NGO advocacy, the MoH has created a budget line to cover RHM home visits. The RHM training curriculum was developed with the participation of the Ministry of Education. Once the planned 16 RHMs are hired (with an additional 16 planned for 2012), they will most likely be based in Macedonia's Roma Information Centers (RICs). These centers are run by partner NGOs, and with funding from

the Ministry of Labour and Social Policy, they assist Roma in accessing social and educational services. RICs also lead the development of local Roma action plans.

Roma health mediation is one of few components of the Decade Action Plan for which the MoH has allocated and spent specific funding. In 2011, the Ministry of Health Preventive Programme for Active Healthcare Protection of Mothers and Children allocated about \$12,000 for approximately 2,500 Roma Health Mediator home visits. This is not a substantial amount, but it represents an important first step in Ministry funding for the Roma Health Mediator program.

The recommendations below suggest ways of making the future RHM program as strong as possible.

- Implement other components of the Decade Health Action Plan. There are several potential synergies between RICs and RHMs. At present, there are no formal links between RICs and health care institutions, but RICs do work with social protection authorities. Roma Health Mediators and RICs can refer clients to one another and ensure that clients who request assistance with health insurance are also receiving the social protection services to which they are entitled. Implementing other components of the Decade Action Plan would provide further opportunities for synergy. Data collection, mainstreaming Roma health concerns into larger governmental health strategies, and training health providers would ensure that mediators are facilitating Roma access to appropriate, high-quality services.
- 2. The RHM program should be carefully monitored by HERA and other stakeholders to measure efficacy and identify program adaptations as needed.
- 3. Provided that the program proves effective, hire additional Roma Health Mediators to ensure that the program can meet the current need. As planned, HERA and others should advocate that the government eventually assumes responsibility for this program.

### 8.3 Romania

Romani Criss, a Roma NGO, started mediation as a conflict mitigation program in 1993. The program was not specifically focused on health, but in 1996, Romani Criss re-oriented the program to improve communication between the medical and the Roma communities. The program was successful, and the government of Romania included Roma health mediation in its 2001 National Strategy for Improving the Situation of the Roma. Romani Criss, the Ministry of Health, and the OSCE's Office for Democratic Institutions and Human Rights signed an agreement to support the national scale-up of mediation in Romania. Romani Criss would train

the Roma Health Mediators, and RHMs would be employees of the public health system. To that end, the Romanian Ministry of Labour added Roma Health Mediator to the official list of occupations in 2001.

The program grew, and by 2002, over 80 RHMs had been trained by and were working for local health authorities. To support the growing number of Roma Health Mediators, in 2006 Romani Criss established a network of regional centers to monitor and provide programmatic assistance to RHMs. Roma health mediation was further institutionalized in Romania when the National Council for the Professional Training of Adults approved occupational standards for health mediation in 2007. At this time, there were 475 RHMs working in Romania.

In 2009, control over many health and social programs in Romania was decentralized, including Roma Health Mediation. Decentralization entailed greater local responsibility for RHM funding and supervision. Local councils were tasked with paying Roma Health Mediators and family doctors began to supervise RHMs.

While decentralization meant that Roma health mediation could be better adapted to local needs, it has had some negative impacts on the RHM program. First, the number of RHMs has decreased. While there were 475 RHMs in 2007, by December 2010, there were 380. Some local councils had opted not to re-hire RHMs due to financial concerns, and others failed to replace mediators who had found other jobs or emigrated. Moreover, the quality of supervision grew to be uneven. Some RHMs report to multiple family doctors, and receive conflicting (or overwhelming) assignments. In other cases, the designated family doctor does no supervising, and Roma Health Mediators are told by the mayor or by social service officials what to do. Roma Health Mediators' autonomy may be lessened; they may play little role in determining how they spend their time. Reporting to doctors has disadvantages as well. Some family doctors may rely on RHMs as "Roma assistants," taking away from RHMs' role as community health organizers.

Finally, with decentralization, the Roma political party has been more involved in Roma health mediation. The party has established county level centers in 20 counties, and in these counties, they have hired RHM Heads. These nominations are often based on party loyalty rather than competence, creating tensions within the community and leading to a decline in the quality of Roma health mediation services.

One hundred and forty five RHMs formed a professional association in December 2010. This association is still in the initial stages, and its role in mediation advocacy and program development remains to be seen.

Romania has the longest running and most institutionalized RHM program in the world. The Romanian program is characterized by strong leadership from a Roma NGO, and ongoing cooperation between this NGO and the government of Romania. With the exception of the last year, the program has grown steadily with increasing numbers of RHMs trained and employed, and the degree of institutionalization growing over time. Romani Criss and its personnel have also become international resources in the development and replication of the RHM model. They have provided technical consultation to other countries and have hosted visitors, including representatives from Macedonia, Serbia, Ukraine, and Moldova.

The following recommendations outline possible improvements for the RHM program in Romania.

- Provide additional training to RHMs to allow them to better implement the tasks included in their current job description. As noted in Annex 2, some RHMs have benefited from continued training. However, this training has been ad hoc, and many RHMs were not able to participate. According to research among RHMs that will be shortly published by Romani Criss, RHMs would like additional training in reproductive health; newborn care; cancer; anti-discrimination legislation; and management topics, such as computer training or proposal development. Moreover, training curricula and records regarding which mediators were trained in what topics should be maintained nationally. At present, this information is not kept.
- 2. Clarify and standardize mediator supervision. Ambiguities date back to the initial Ministerial Order establishing the RHM program, which is unclear. As the Order was translated by the country consultant, Ms. Nicoleta Bitu, the Order assigns supervisory responsibility to county health authorities and to Romani Criss, without adequately specifying who is responsible for which supervisory tasks. In the context of decentralization, this lack of clarity has been exacerbated, with RHMs reporting to multiple family doctors or to persons of the mayor's choosing. Issuing a clarifying ministerial order and ensuring some degree of standardization among counties would help ensure that mediators receive the supervision they require, remain able to exercise their autonomy and expertise, and continue with important community building and organizing work.
- 3. Ensure the continued employment of existing RHMs, and hire new mediators in areas where local councils have failed to renew contracts. Salary freezes should only be imposed as a last resort, and if imposed, should be consistent with salary freezes for comparable health professionals.
- 4. Ensure that the involvement of the Roma political party does not result in the deterioration of the quality of the RHM program. RHMs should be hired, trained, and supervised based on their capabilities—not on their relationship to a political party.

### 8.4 Serbia

The Serbian Ministry of Health initiated Roma health mediation in 2008 with OSCE and European Agency for Reconstruction support. There are now 75 RHMs employed by local self-governments. Forty-five of the RHMs are paid by a project-based budget line of the MoH, 15 by a World Bank loan, and 15 by the Open Society Foundations.

CARE International has trained an additional 95-100 RHMs in Southern Serbia. This program ran from 2008 to July 2011. Ten of these mediators are currently employed as RHMs by the Ministry of Health or as pedagogical assistants. These RHMs were never part of the Serbian national program.

Roma Health Mediators are based in health centers, though they conduct frequent field visits. They report to visiting nurses, as well as to the RHM Coordinator based in the MoH. Reporting to the MoH is done mostly through submission of electronic reports on laptops donated by Telenor, a Serbian mobile phone operator. Telenor has also donated mobile phones, SMS messaging, and internet, and UNICEF has coordinated the donation. UNICEF is providing additional training to the RHMs in data collection and reporting, and in the importance of monitoring public health programs.

In 2011, UNICEF will also train 15 RHMs and other health providers in Southern Serbia on early childhood development topics.

RHMs are tasked with visiting every family in the area covered by the health center in which they are based. They should assess the needs of each family and provide services such as referrals to health care or to social services, assistance in setting up these appointments, health education on family and adolescent health topics or hygiene, and assistance obtaining documentation or registering with a general practitioner. In addition, in collaboration with visiting nurses, RHMs may organize community-based screening efforts, such as blood pressure and blood sugar level checks. RHMs coordinate their personal documentation-related activities with the Ministry of Public Administration and local self-government working groups that have been established to address personal documentation.

The Serbian program is somewhat unique in that RHMs are part of a relatively strong network of professionals working to foster social inclusion at the local level. Serbia also has 180 Roma pedagogical assistants (education mediators), who are tasked with increasing access to education. Moreover, there are 54 Roma Coordinators working within the local self-governments. These coordinators spearhead the development of local action plans, and develop project proposals based on these plans. Successful proposals are funded by the central government, and some funded projects involve RHMs and Roma NGOs. However, tensions have arisen in some locales, with RHMs reportedly having been instructed to not share information with other public sector employees.

### **Telenor Donation**

Roma Health Mediators frequently use SMS messaging to communicate with their clients and remind them of their appointments. Therefore, lack of access to mobile phones, air time, and SMS messaging is a problem for RHMs in several countries. Donation from a private mobile phone provider such as Telenor is one possible solution. Free SMS messaging ensures that mediators are not constrained by financial concerns.

The following recommendations suggest ways of strengthening the existing program.

- I. Consider making Roma health mediation a recognized profession. Institutionalizing the profession of Roma health mediation may aid the standardization of training and promote the financial sustainability of the program. It may also facilitate the integration of RHMs into the overall health system, fostering greater respect for RHMs within the health facilities where they are based.
- 2. Clarify the respective roles of RHMs, visiting nurses, and pedagogical assistants. As noted, there is enormous potential for synergies among these programs. However, interviews suggest that in some cases, there is confusion and competition among these programs.
- 3. Better integrate RHMs into health centers. In some cases, RHMs are reportedly not well accepted by the health centers in which they are based. They are asked to sit in halls rather than being given a workspace, and ignored by other health personnel. Including RHM colleagues, such as patronage nurses and other health center staff in continuing training may help to create a commonly agreed way of cooperating.
- 4. Expand the Telenor donation to include minutes for phone calls. At present, RHMs only have free SMS messaging. As some of their clients are illiterate, RHMs must phone these clients in order to communicate with them.
- 5. If feasible, change RHM contracts to require annual renewal, rather than renewal every 3 months.
- 6. Explore the feasibility and utility of drawing on the experiences of the RHMs trained by CARE in Southern Serbia. These mediators benefited from very intensive training and support, and their training curricula and experiences may benefit the Ministry of Health Program.

### 8.5 Slovakia

Roma health mediation began in 2005 as part of a larger PHARE-funded Roma community center project. As part of this project, 140 community centers were created and 42 RHMs were trained, though only 30 are still working. These community centers are located in Roma settlements, and provide a place for activities, such as Roma health mediation, recreational activities, community meetings, and so on. An additional 18 RHMs in Slovakia were trained and supported as part of an Open Society Foundations project, but this project has ended (some of the OSF-trained RHMs continue to work on a voluntary basis).

Roma Health Mediators hired under the initial PHARE project benefited from a national training led by the Ministry of Health. Roma NGOs participated in designing the curriculum. However, in 2007, training, management, and funding responsibility for Roma health mediation was decentralized to local Offices of Public Health (OPH). Management and funding for the Roma community centers were also decentralized. Thus, RHMs hired since 2007 have been trained and supervised by their local OPH. As part of their supervision, RHMs spend one day per week at the OPH, recording their activities for the past week and planning the following week. Some RHMs also spend I or 2 days conducting health education sessions and receiving clients at the Roma community centers.

As the governmental RHM program structure has changed, so too have Roma Health Mediator responsibilities. RHMs were initially focused on explaining the health system to the community and on documenting housing conditions. Now, they are tasked with facilitating communication between Romani patients and physicians, and conducting health education in the community. As part of their health education efforts, RHMs should identify community leaders and target them to model healthy behavior change. Roma Health Mediators do not work on personal documentation and insurance, as there are very few Roma who lack personal documentation or health insurance in Slovakia. Mediators do however assist clients who have lost their birth certificate, and the few who do not understand how to obtain a health insurance card. They also provide linguistic translation for clients who do not speak Slovak well.

Roma Health Mediators in Slovakia collaborate with family physicians, but they generally do not cooperate much with other field-based public sector employees. This is in part because the Slovak government has cut these sectors in recent years. Community nursing has been eliminated, and the number of social workers has decreased. There are few community centers served by both RHMs and social workers.

Although the Slovak RHM program has been operational for 6 years, it is less institutionalized than other programs that have been operating for about the same length of time, namely Bulgaria and Romania. Moreover, there are comparatively fewer Roma Health Mediators (per Roma population) working in Slovakia. Finally, as noted, the program has been plagued by contract insecurity, with RHMs having to get their contracts renewed every yearoften with great delay. This undermines RHM morale and the trust they cultivate in communities. The reasons for the differences between Slovakia and other countries are likely numerous. Lack of a strong NGO partner and lack of political will may explain some of the differences.

The following Slovakia specific recommendations outline concrete suggestions about how to improve the RHM program in Slovakia.

- Increase the number of RHMs. There are few mediators compared to the size of the Slovak Roma population. The need to hire more Roma Health Mediators was already identified in Slovakia's own national Roma strategy—the "Medium-term concept of the development of the national Roma minority in the Slovak Republic."
- 2. End contract insecurity. Due to regular problems with contract renewal and budgetary allocations, some RHMs work 75% of every year. This model is less effective than a sustainable, longer term program. Roma Health Mediators feel less secure in their positions and may seek employment elsewhere. Members of Roma communities served by RHMs see that Roma Health Mediators are not "there to stay," and they are less likely to trust and respect RHMs. Supporting a cadre of RHMs and other professionals to have a sustainable role over several years would better contribute to lasting change. Creating new public sector positions in Slovakia is achievable. For example, between 2002 and 2003, the Slovak government created 1,814 civil service positions required for EU accession.<sup>75</sup> The government has thus created public sector positions since the democratic transition, and should do so for RHMs.
- 3. Provide more training to current RHMs. Some RHMs hired in 2005 have not received any continuing education. Roma Health Mediators hired since 2007 were trained by their local OPH, and have received training of varying quality and depth. In focus groups and interviews, Roma Health Mediators expressed a strong desire for further training. Additional training for the 35 RHMs currently working would not require significant costs, and would help to improve Roma Health Mediator competence and morale. Roma Health Mediators themselves should be consulted regarding the content of such continuing education.

### 8.6 Ukraine

Ukraine is somewhat dissimilar from the other countries included in this review. First, Ukraine is not a member of the Decade of Roma Inclusion. Second, Ukraine is not seeking membership in the EU, meaning that the country is not eligible for much of the funding that has supported Roma Health Mediation projects in other countries. Third, the number of Roma as

a percentage of the overall population in Ukraine is comparatively small. Nonetheless, many Roma in Ukraine experience the health and social exclusion characterizing isolated Roma communities elsewhere in Europe. Moreover, the government of Ukraine has taken the important step of supporting the establishment of an RHM program. As the program in Ukraine is just being launched, Ukrainian program planners can learn from other country experiences to make modifications to their own program.

Ukraine does not have a national strategy for Roma inclusion. The government had such a strategy in the past, but it expired in 2006. The Ministry of Health had issued a Ministerial Order related to the implementation of this earlier Roma strategy, but they never allocated any funding. Many individuals within the government do not see the need to allocate funding for Roma-specific activities; they claim that the Roma are treated the same as all Ukrainians. (This stance had previously been very prevalent among Decade countries). Ukraine does not have a ministry tasked with facilitating the inclusion of ethnic minorities, although they have had such a ministry in the past. As of now, governmental representatives reported that the government has no intention of developing a Roma inclusion strategy.

Roma Health Mediation is included in the 2011 action plan of the Ministry of Labour and Social Policy, which foresees some innovative actions to promote social inclusion in Ukraine. In addition to Roma health mediation, the plan includes developing a strategy for the homeless (many Roma currently living in Ukraine are officially classified as homeless), implementing a program to inform eligible persons about their rights to social assistance, and developing an anti-poverty strategy. Ministry of Health involvement in mediation will be limited to providing printed health education materials to RHMs and to cooperation on the local level on vaccination and other campaigns.

The Roma health mediation project started in 2010, when NGO actors held strategy and consensus building meetings with relevant governmental and nongovernmental bodies. The first RHMs were hired in April 2011 with funds from the Open Society Foundations. The current grant ends in January 2013. The Roma NGO Chirikli is coordinating the project. Chirikli has hired and trained 14 RHMs to work in five pilot regions. The Center of Family Matters of the Kiev State Administration, the State Center for Employment, and the Ministries of Justice and Labour and Social Policy provided technical and programmatic support to the training. Specifically, governmental representatives attended the training and gave lectures relevant to their mandate. Chirikli will document the results of the Roma health mediation program, and then use the results to advocate for scale up and institutionalization. Institutionalization might entail registering the profession of Roma Health Mediator; transferring overall programmatic, financial and logistical responsibility for the program to the government; and identifying sustainable sources of funding at the regional (rayon) level.

Not all of the RHMs hired are Roma: three are Hungarians and two are Ukrainian. These Roma Health Mediators will work with Roma who speak the Hungarian or Ukrainian languages.

So far, Ukrainian RHMs have worked primarily on assisting Roma clients with personal registration, since many (approximately 14,000) Roma still had registration papers dating from the Soviet Union. RHMs have also provided health education and helped clients to obtain passports, receive vaccinations for which they were overdue, and schedule medical appointments. Roma Health Mediators make 3-month work plans, and their work is supervised by Chirikli. Chirikli is also involved in an Inter-Ministerial Council on Social Issues, which is tasked with devising policies to address individuals without personal documentation, the homeless, and the formerly incarcerated. Roma are over-represented in these groups.

The RHM program in Ukraine is quite young, so it is premature to make recommendations. However, it is timely to stress that the Ministry of Labour and Social Policy should continue to support the program, and Chirikli and the Open Society Foundations should carefully document program results. The overall recommendations in the following section may also be useful for developing the RHM program in Ukraine.

# 9. Overall Recommendations

The following recommendations can generally be applied to all countries included in the current review. The first section outlines recommendations for mediation programs, and the second section outlines recommendations for governmental efforts to promote social and health inclusion.

### 9.1 Roma Health Mediator Program Recommendations

I. Ensure the institutionalization of Roma Health Mediator programs. Roma Health Mediation is a medium-term solution; in the long term, health and social services should be equally accessible to all residents of a country. However, in order to have maximum impact now, Roma health mediation must be sustained and supported by the government. Governments in countries with new programs, such as Macedonia and Ukraine, should ensure that these programs are eventually managed and financially supported by the government, with NGOs playing an advisory role. Governments of countries with established programs, such as Bulgaria and Romania, should seek greater formalization and recognition of RHMs and mediator associations.

- 2. Include doctors, visiting nurses, social workers, and other relevant professionals in some portion of Roma Health Mediator trainings and professional events. As noted, some RHM programs have included doctors and others in some trainings. Including doctors and others on an ongoing basis will promote cooperation and mediation effectiveness. Moreover, it will build provider capacity to address excluded Roma clients.
- 3. Support the development of RHM professional associations. Only Bulgaria and Romania have such associations. RHM associations provide an opportunity for information sharing, professional development, and moral support. Donors and/or government support for the development of professional associations would further promote the empowerment objectives of Roma Health Mediator programs.
- 4. Ensure that RHM program monitoring focuses on outcomes as much as possible. As explained, lack of baseline data makes it difficult to assess the impact of Roma health mediation programs. However, current data collection systems could be strengthened to better track outcomes. For example, rather than simply recording the number of persons who were assisted with documentation, RHMs might track the number who ultimately received documents. Similarly, numbers tracking vaccination should be disaggregated based on those who were counseled to get vaccinated, and those who actually got vaccinated. This more careful monitoring might detract from Roma Health Mediators' ability to perform other tasks, but in some countries, collecting data to make the case for mediation is urgent and would justify such a re-orientation of priorities.
- 5. Ensure supportive supervision. RHMs can learn more and function better with supportive supervision. Allocating adequate resources (e.g. for the cost of human resource time, travel, tool development, etc.) is essential to ensuring the investments in Roma health mediation pay off as much as possible. Where decentralization of Roma health mediation responsibility occurs, program planners should ensure consistent and standard quality of supervision. Adequate role definition and resource allocation are essential.
- 6. Increase the number of Roma Health Mediators to meet the current needs of the population they serve. Roma Health Mediators make a difference in the communities in which they work. If there are many communities without RHMs, it is inconceivable that RHMs will influence average Roma health status in the country. More RHMs are needed to impact national level statistics.
- 7. **Ensure continuing education.** This need is more outstanding in some countries than others, but it would be helpful in all countries. Continuing education would improve RHM practice and morale, and advance the goal of empowering RHMs. Both governments and mediator professional associations could organize such trainings.

- 8. Create opportunities for health and social policy officials to learn from RHM experiences. Again, because of their everyday experiences in excluded Roma communities, RHMs are experts on the opportunities and challenges to improved Roma health. They should be consulted by governmental and other program planners so that their expertise can inform Roma inclusion policy and social inclusion policy more broadly. Using RHM expertise to improve other programs would be another way of ensuring that the investment in Roma health mediation is as cost-effective as possible. Health and social authorities could also establish formal relationships with RHM professional associations.
- Ensure that RHMs have a secure contract and salary. Interruptions in contracts and sal-9. ary undermine RHM effectiveness, as community members lose trust in Roma Health Mediators. Moreover, contract insecurity undermines the goal of RHM empowerment, as contract insecurity suggests that mediator work is not valued. Finally, lack of reliable employment for mediators contributes to high turnover, and thus higher program costs in training and orienting new mediators.
- Ensure that Roma Health Mediators earn a living wage. As noted, in some cases, RHM 10. salaries are lower than other health sector salaries. In other cases they are not, but all health sector salaries are low. Paying all health workers a living wage is crucial to promoting morale and ensuring that the most qualified and committed individuals enter the field.
- Ensure that RHMs have the money and other tools for required tasks. Roma health II. mediation is somewhat different than other health sector positions in that extensive field work is required. This field work entails costs related to transport, communication, and printing. Many mediators are either faced with not performing needed tasks or funding these costs themselves.

### 9.2 Health and Social Policy Recommendations

Ensure that health education materials RHMs and others distribute are adapted for Ι. Roma and other diverse audiences. As explained, in several countries, some of the materials that are distributed are text heavy and difficult to understand. Materials should be developed based on an assessment of existing community knowledge and beliefs, and they should be pre-tested with the target community before printing. Materials specifically for Roma should be affirming of Roma cultural values. Donors and governments have repeatedly funded the development of small-scale information campaigns. Funding more costly programs that result in more appropriate materials would be a better use of money.

- 2. Better integrate Roma health concerns into health policy. First, RHMs should be better integrated into the health system. In addition to interacting and training with other health professionals, they should be given opportunities to share their experiences. Second, broader health strategies, such as those for maternal and child health, tobacco control, and at-risk children, should include measures specific to the Roma. Devising measures specific to excluded Roma populations might entail making services culturally appropriate, ensuring that remote communities are reached with services, ensuring that services are accessible to those with limited education, and so on.
- 3. Ensure that other steps are taken to reduce poverty among the Roma, and to provide basic services to all citizens. Roma health mediation is ill-equipped to deal with the poverty many of its clients experience. Moreover, Roma health mediation cannot address the fact that basic health services may cost money. Ensuring adequate social protection schemes and a robust basic benefits package (package of health care services that are free to everyone) will help. Implementing the Decade Action Plan in other areas—employment, education, and housing—will also contribute to decreased poverty and remedy poverty-related barriers to improved health.
- 4. Collect health data disaggregated by ethnicity and sex, among other attributes. Governments could either conduct surveys regarding Roma health and socio-economic status, or ethnically disaggregate their regular systems of data collection. As explained, good data is germane to designing appropriate programs, and to measuring program effectiveness.
- 5. Ensure that laws relating to personal documentation and health insurance coverage are not too onerous for Roma and other excluded groups. RHMs in many countries spend a good deal of time assisting clients with documentation and health insurance. In some countries, other programs have been created to address documentation. In Macedonia for example, UNHCR has a project to assist Roma and others with obtaining documentation. Moreover, as noted, both Macedonia and Serbia have changed their health insurance eligibility laws to facilitate universal coverage. Countries with persistent problems with documentation and insurance might consider whether having mediators assist clients with documents is the best use of mediator time. Other options include creating documentation-specific programs and changing the laws governing documentation and health insurance coverage.
- 6. Take steps to increase routine vaccination coverage. RHMs are often involved in vaccination campaigns or in tracking down clients who fail to appear for scheduled vaccinations. Vaccination is also a key component of RHM health education efforts. These RHM interventions likely save lives. However, it is imperative that routine vaccination

services consider how they can be more accessible, rather than relying on mediators to assist over the long-term. Qualitative data collection within Roma communities regarding the reasons for lower rates of vaccination is needed. Free travel to health facilities for scheduled vaccinations and the creation of appropriate and innovative health education methods (such as plays or Romanes language TV spots where Romanes language television exists) might help to decrease the need for mediator involvement in vaccination over the long-term.

- Engage Romani men in sexual and reproductive health programs. In countries where 7. RHMs are unable to do this due to cultural norms, the government should ensure that other programs reach men. As noted, men are often the more powerful decision-maker in family planning discussions. Reaching men may be difficult; they are not traditionally subjects of health promotion programs, and they may be very reluctant to discuss sexual and reproductive health issues. Nonetheless, successful programs have been created in settings with similar obstacles, and relevant elements could be replicated in Roma communities. For example, Promundo, a Brazilian NGO that now works globally, has created a global toolkit for engaging men and boys in health and gender equality.<sup>77</sup>
- 8. Design strategies and programs that take a community-building approach to Roma health—not a hierarchical approach. Approaching program planning and implementation in a top-down manner reinforces the exclusion and dependence of excluded Roma communities. Mediation and other programs should be based on an understanding of the reasons for Roma exclusion, not negative assumptions about Roma health habits.
- Leverage the growing EU focus on health equity and Roma inclusion to support media-9. tion and other health efforts. Governments should think strategically about how to leverage the growing European focus on health equity and Roma inclusion to support costly improvements to data collection systems, to collect original data, to "audit" governmental health and social policy strategies for their focus on Roma and equity, and so on. Innovative ESF, EU public health program, and Instrument for Pre-accession Assistance (IPA) proposals that respond to the health equity and inclusion agenda would be strong candidates for funding.
- Ensure that mediation is part of a continuum of services available to excluded Roma 10. and other populations. First, RHMs can be most effective when they operate as part of a network of service providers and advocates. Roma Health Mediators should know where to refer clients who experience discrimination, who need assistance with school enrollment, who wish to legalize a dwelling and so on. Second, RHM cooperation with other providers will build those providers' capacity to work with excluded Roma. This will

improve the quality of those providers' services in the short-term, and help to decrease the need for Roma health mediation in the long-term.

Increase the number of Roma health and social service professionals. Roma who wish to work on social or health issues in their community should have more options than becoming an RHM or working for an NGO. Where they do not exist, scholarship schemes, child care for women enrolled in higher education, language learning assistance, and other programs are needed to increase the number of Roma health and social service professionals. Greater Roma representation among public sector professionals should also contribute to wider cultural competence and commitment to ending Roma exclusion within these professions.

## Annexes

### Annex 1: Roma Health Mediator Questionnaire

The following questionnaire was translated in each country.

### Questionnaire

Please put a	ı number 1–5	to indicate	how	frequently	you	encounter	the	following	issues	in
your work.										

- 1: very frequently
- 2: frequently
- 3: sometimes
- 4: not very often
- 5: never

The client disagrees with the treatment the physician proposes
The client does not trust the treatment the physician proposes
The client has not followed the treatment the physician proposed in the past

The client incorrectly expected that the treatment would be effective in a short time
The health professional does not understand the client's behavior
The health professional does not sufficiently consider the client's culture
The health professional makes incorrect assumptions about the client based on the fact that s/he is Roma
The health professional has a negative attitude towards the client
The health professional is condescending to the client
The client does not speak enough X language to make himself understandable
The client does not speak enough X language to understand the health professional
The client does not sufficiently assert his/her rights
The health professional does not make enough effort to help the client
The health professional misuses his/her powerful position
The health professional explains too little about the disease or treatment
The client does not have enough money to pay for the treatment
The client's living circumstances are not conducive to treatment
The client does not have health insurance
The client does not have citizenship
The client does not trust the health professional enough to provide him with details about an illness

## ANNEX 2: RHM Training and Job Requirements

	Bulgaria
Training	Training has been approved by the government, considered to be an official qualification. The training is 150 academic hours (about 4 weeks of all day training). Since 2007, municipalities hiring mediators have financed the training. Candidates are selected by municipalities with input from the National Network of Health Mediators.
Content of primary training	<ul> <li>Main tasks of the RHM</li> <li>Organization of their work</li> <li>Reproductive health</li> <li>Diseases of public health importance</li> <li>Patients' rights</li> <li>Entitlements and Bulgarian health care legislation</li> <li>Communication skills</li> <li>Health and multiculturalism</li> <li>Leadership and teamwork</li> <li>Client needs assessment</li> <li>Project management</li> </ul>
Requirements	<ul> <li>Completed high school</li> <li>Recommendation from previous employers</li> <li>Completion of an essay regarding why they would like to be a health mediator</li> <li>Knowledge of Romanes and/or Turkish (where relevant) preferred</li> </ul>
	Macedonia
Training	The training was developed by the Ministry of Education, with input from HERA and the MoH. The first phase of the training was completed in August, 2011.
Content of primary training	<ul> <li>How to assist clients in accessing health care</li> <li>Health promotion (particularly for preventive check-ups, immunization, and healthy lifestyles)</li> <li>How/where to refer clients for social protection services</li> <li>How to accompany clients (going with clients to services) in accessing health care or social protection</li> <li>Communication skills, including facilitating patient/provider communication and translating medical concepts into simple language</li> </ul>
Requirements	Completed high school (with a preference for those with some medical or other relevant training) Good knowledge of Macedonian language as well as the language spoken by the Roma population in the area Good communication skills Priority given to women, but men are eligible Is accepted by the community Priority given to those who work with NGOs and already have relevant experience

#### Romania

Training provided by the Ministry of Health. The National Council for the Professional Training of Adults has certified two associations and one university to provide continuing education to the mediators, although Romani Criss trains the majority of the mediators (and there is no centrally available information regarding how many these agencies have trained). Romani Criss is a Roma NGO that has played a key role in Roma health mediation from the program's inception. Local health facilities provide the space for the training. Local NGOs, including the Roma Party, are involved in selecting the mediators to be trained. Ongoing training is provided to some mediators according to need and based on the availability of additional funds. Additional training has been provided on issues such as: human rights, how to obtain identity documents, how to prevent TB, how to support TB treatment, family planning and reproductive health, vaccination, and pregnancy and newborn care. Training on reproductive health was provided by John Snow International and on TB was provided by Doctors of the World-USA and the Ministry of Health. Finally, through a PHARE program running from 2004 to 2006, the government trained trainers on Roma Health Mediation, and elaborated a manual for health mediators.

# Content of primary training

- Communication
- · Legislation regarding health insurance
- Key tasks of RHMs
- · Key determinants of Roma health

# Requirements

· At least 8th grade education. However, forty two percent of mediators currently working have completed high school or above.

#### Serbia

Training provided by the Ministry of Health, with technical input solicited from Roma NGOs and from the Standing Conference of Cities and Municipalities. The Council for the Improvement of the Status of Roma (Council is in the Office of the Deputy Prime Minister for European Integration) also conducted some sensitization trainings on working with Roma for Health Centres. UNICEF is providing additional training on data collection and reporting, and the importance of monitoring public health programs. UNICEF will also train 15 mediators and other service providers based in Southern Serbia in early childhood development.

# Content of primary training

- Key tasks of RHM
- Health and social protection system, including costs for various services
- Organization of their work (reporting, planning and so on)
- Maternal, reproductive, and child health topics
- · Adolescent health and addiction concerns
- · Chronic diseases and health behaviors
- · Awareness raising about domestic violence and trafficking
- Communication
- RHM code of conduct
- UNICEF: early childhood development

# Requirements

- · Completed primary school
- · Be female and a mother

### Slovakia

## gninir

From 2005 to 2007, RHMS were hired and trained at the national level. Since 2007, RHMs have been selected at the local level. The initial group was trained by the MoH. Now, they are trained by the local Offices of Public Health (which is part of the MoH). The mediators have different training backgrounds. Those employed since 2005 have participated in several trainings, and those hired more recently were trained only by the local Office of Public Health, with the curriculum largely decided at the local office.

# Content of primary training

#### Main tasks of the RHM

- Organization of their work (reporting)
- Public health topics presented through lectures at the local Office of Public Health. Topics subject to the discretion of the Office

# Requirements

### Completed high school

- · Preference given to those with medical background
- · Romani language knowledge preferred

#### Ukraine

# aining

RHMs were selected and trained by the NGO Chirikli, with training support provided by Center on Family Matters of the Kiev State Administration, the Ministries of Justice, Labour and Social Policy; and the State Center for Employment, and a professor from a local university. Romani Criss also provided input and technical support. So far, only one training has been conducted, as the program has just started. However, RHMs have already benefited from additional human rights, empowerment, and intercultural mediation training provided by the Council of Europe.

# Content of primary training

- Main tasks of the RHM
- Organization of their work (reporting, planning and so on)
- · Communication skills
- Facilitating patient-provider communication
- · Principles of confidentiality
- RHMs are also provided with a book for "Frequently asked questions" they can refer to when asked questions about processes for updating identity documents, and so on.

# Requirements

- · Completed high school (priority given to those with a diploma in health or other related area)
- Proficient in Ukrainian and the language spoken by the Roma in the area they live
- · Accepted by the community
- · Strong communication skills
- · Priority given to mothers but men may also be selected as mediators

### ANNEX 3: Roma Health Mediator Costs and Benefits

#### Fixed Costs

- Management costs (manager salary, manager office space, manager computer, monitoring and evaluation, fundraising, etc.)
- RHM program design costs

### Sost

### Variable Costs

- Roma Health Mediator salaries
- Roma Health Mediator activity costs (health education materials, travel and communication funding, etc.)
- · RHM training and continuing education
- · Roma obtain birth registration, identity documents, and health insurance
- Increased use of preventive care, including regular check-ups, family planning services, gynecological exams, sexual health services, and vaccination
- Improved efficacy of health care visits where mediators are present, and after several such visits with mediators, improved efficacy in the absence of mediators
- · Roma awareness about health and social protection entitlements raised
- Other governmental and non-governmental programs for Roma enhanced by input from mediators

# • Health provider knowledge about Roma exclusion (and culture) improved, some health care providers report changing their behavior toward Roma patients

- Roma clients referred to social assistance, housing, psychosocial, and other services
- Roma mediators become leaders and role models in communities where unemployment is high and opportunities appear to be rare
- · Community trust in public services enhanced
- Mediators trained, and some go on to higher education in nursing, social work, and medicine

# nefits78

# Works Cited in Text Boxes

Berdzuli, N., Ippolito, L., & Haffey, J. (2008). Supportive Supervision: Training of Trainers and External Supervisors (Facilitator's Guide). Boston: John Snow Incorporated. (http://usaid.gov/locations/europe\_eurasia/health/docs/final\_supportive\_supervision.pdf, accessed 13 July 2011).

Commission of the European Communities. (2007). White paper: together for health a strategic approach for the EU 2008-2013. COM(2007) 630 final (http://ec.europa.eu/health-eu/doc/whitepaper\_en.pdf, accessed 16 July 2011).

European Commission. (2011). An EU Framework for National Roma Integration Strategies up to 2020. COM(2011) 173 final (http://ec.europa.eu/justice/policies/discrimination/docs/com\_2011\_173\_en.pdf, accessed 1 October 2011).

WHO. (1986). Ottawa Charter for Health Promotion. WHO/HPR/HEP/95.1. (http://www.who.int/hpr/NPH/docs/ottawa\_charter\_hp.pdf, accessed 16 July 2011).

## Notes

- I. The words "Roma community," "excluded Roma" and "isolated Roma settlements" are used throughout this report. The second two terms are used to emphasize the fact that Roma Health Mediators work primarily with excluded Roma, and not just Roma in general. Indeed, there are Roma who live in adequate housing, and who have access to secure employment and health services. These individuals do not require Roma Health Mediation.
- 2. It is impossible to track exactly how much money has been allocated to Roma health, although a cursory review of country projects shows that it is less than other sectors, particularly education. Tracking health expenditures is difficult because governments do not necessarily keep a central database of funds allocated by international donors, EU funding, and governmental funding. Moreover, there are often vast discrepancies between what is allocated and what is actually spent. For obvious reasons, governments may not wish to publicize this discrepancy.
  - 3. See: www.romadecade.org.
  - 4. See: http://ec.europa.eu/enlargement/index\_en.htm.
- 5. See: http://ec.europa.eu/enlargement/how-does-it-work/financial-assistance/phare/index\_en.htm.
- 6. "Community instruments" refers to EU legal, financial, and coordination instruments. Legal instruments include the Race Equality Directive and the Framework Decision on Racism and Xenophobia. Financial instruments include the European Social Fund, pre-accession support, and other mechanisms. Coordination instruments include frameworks for European social policy

coordination, such as the Open Method of Coordination. See the full description of the principles for more information: http://ec.europa.eu/social/main.jsp?catId=761&langId=en.

- 7. European Commission: Employment, Social Affairs and Inclusion. (2011). Platform for Roma Inclusion. European Commission website. (http://ec.europa.eu/social/main.jsp?catId=761&langId=en, accessed 5 July 2011).
- 8. Commission on the Social Determinants of Health. (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Geneva: World Health Organization.
- 9. European Commission. (2011). An EU framework for national Roma integration strategies up to 2020. Comm (2011)173/4. Brussels: Belgium.
- 10. European Commission. (2011). Commission calls on EU countries to set national strategies for Roma integration. European Commission website. (http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=1011&furtherNews=yes, accessed 5 July 2011).
- II. Open Society Foundations. (2010). No data no progress: data collection in countries participating in the Decade of Roma Inclusion 2005–2015. Budapest: Open Society Institute. (http://www.soros.org/initiatives/roma/articles\_publications/publications/no-data-no-progress-20100628/no-data-no-progress-20100628.pdf, accessed 5 July 2011).
- 12. European Commission. (2009). Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions—Solidarity in health: reducing health inequalities in the EU. COM/2009/0567 final. (http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2009:0567:FIN:EN:HTML, accessed 16 July 2011).
- 13. "Ethnically disaggregated" data shows the differences among ethnic groups. So, with ethnically disaggregated data, governments would know what the key health differences are between Roma and the population overall.
- 14. Committee of Ministers, Council of Europe. Rec(2006)18. Recommendation of the Committee of Ministers to member states on health services in a multicultural society. (http://www.coe.int/t/dg3/health/recommendations\_en.asp, accessed 6 July 2011).
- 15. Committee of Ministers, Council of Europe. Rec(2001)12. (http://www.coe.int/t/dg3/health/recommendations\_en.asp, accessed 6 July 2011).
- 16. Council of Europe. (2010). Council of Europe High Level Meeting on Roma Strasbourg, 20 October 2010 "The Strasbourg Declaration on Roma." CM(2010)133. (www.coe.int/t/dc/files/source/2010\_cm\_roma\_final\_en.doc, accessed 6 July 2011).
- 17. Council of Europe. (2011). European training program for Roma mediators. Brussels, Council of Europe; Aurora Alincai, Administrator, Council of Europe. Personal communication with the author, 24 February 2011.

- 18. Council of Europe. (2011). European Commission and Council of Europe step up work for Roma with mediators. Press release DCo45(2011). (https://wcd.coe.int/wcd/ViewDoc.jsp?id=181141 7&Site=DC&BackColorInternet=F5CA75&BackColorIntranet=F5CA75&BackColorLogged=A9BACE, accessed 6 July 2011).
- 19. European Council. (2006). Council conclusions on common values and principles in European Union health systems. (2006/C 146/01).
- 20. Commission of the European Communities. (2007). Together for health: a strategic approach for the EU 2008–2013. Brussels: Commission of the European Communities. COM(2007) 630 final. (http://ec.europa.eu/health-eu/doc/whitepaper\_en.pdf, accessed 7 July 2011).
- 21. See: World Health Organization. (2010). Poverty and social exclusion in the WHO European Region: health systems respond. Copenhagen: World Health Organization. (http://www.euro.who.int/\_data/assets/pdf\_file/0006/115485/E94018.pdf).
- 22. Jennie Popay, Professor of Sociology and Public Health, Lancaster University. 15 February 2011, personal communication with the author.
- 23. Orlikova, H., Rogalska, J., Kazanowska-Zielinksa, E., Jankowski, T., Slodzinski, J., Kess, B., and Stefanoff, P. (2010). Spotlight on measles 2010: a measles outbreak in a Roma population in Pulawy, eastern Poland, June to August 2009. *European Surveillance*, 15(17):pii–19550; Kraigher, A. et al. (2006). Vaccination coverage in hard to reach Roma children in Slovenia. *Collegium Antropologicum*, 30(4):789–794; Loewenberg, S. (2006). The health of Europe's most marginalised populations. *Lancet*. 368(9553):2115; Georgakopoulou, T. et al. (2006). Current measles outbreak in Greece. *Eurosurveillance*, 11(2).
- 24. Koupilová, I. et al. (2001). Health needs of the Roma population in the Czech and Slovak republics. *Social Science & Medicine*, 53:1191–1204.
- 25. Rambouskova, J., Dlouhy, P., Krizova, E., Brochazka, B., Hrncirova, D., and Andel, M. (2009). Health behaviors, nutritional status, and anthropometric parameters of Roma and non-Roma mothers and their infants in the Czech Republic. *Journal of Nutrition Education and Behavior*, 41(1):58–64; Bobak, M. et al. (2005). Unfavourable birth outcomes of the Roma women in the Czech Republic and the potential explanations: a population-based study. *BMC Public Health*, 5:106.
- 26. Koupilová, I. et al. (2001). Health needs of the Roma population in the Czech and Slovak republics. *Social Science & Medicine*, 53:I191–I204.
- 27. Ionita, M., Nastase, M., and Mihaescu, T. (2001). Tuberculosis in a rural gypsy community—Romania. *European Respiratory Journal*, 18(Suppl. 33):S323 (abstr.)
- 28. Schaaf, M. (2010). Roma health. In: Poverty and social exclusion in Europe, health systems respond. Copenhagen: World Health Organization.
- 29. EU FRA. (2009). Data in focus report: the Roma. Vienna: European Union Fundamental Rights Agency. (http://www.fra.europa.eu/fraWebsite/attachments/EU-MIDIS\_ROMA\_EN.pdf, accessed 7 July 2011).

- 30. Ringold, D., Orenstein, M.A., and Wilkens, E. (2005). Roma in an expanding Europe: breaking the poverty cycle. Washington, D.C., World Bank (http://siteresources.worldbank.org/EXTROMA/Resources/roma\_in\_expanding\_europe.pdf, accessed 15 March 2011).
- 31. Smith, G.D. (2000). Learning to live with complexity: ethnicity, socioeconomic position, and health in Britain and the United States. *American Journal of Public Health*. 90(11):1694–8; Nazroo, J.Y. (2003). The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism. *American Journal of Public Health*, 93(2):277–284; Krieger, N. & Sidney, S. (1996). Racial discrimination and blood pressure: the CARDIA study of young black and white adults. *American Journal of Public Health*, 86(10):1370–1378. Krieger, N., Carney, D., Lancaster, K., Waterman, P.D., Kosheleva, A., and Banaji, M. (2010). Combining explicit and implicit measures of racial discrimination in health research. *American Journal of Public Health*, 100(8):1485–1492; Williams, D.R., Neighbors, H.W., and Jackson, J.S. (2003). Racial/ethnic discrimination and health: findings from community studies. *American Journal of Public Health*, 93(2):200–208.
- 32. Ingleby, D. (2010). How health systems can address health inequities linked to migration and ethnicity. Copenhagen: World Health Organization.
- 33. Kosa, K., Molnar, A., McKee, M., and Adany, R. (2007). Rapid health impact appraisal of eviction versus a housing project in a colony-dwelling Roma community. *Journal of Epidemiology and Community Health*, 61:960–965; Monasta, L., Andersson, N., Theol, D. & Cockcroft, A. (2008). Minority health and small numbers epidemiology: a case study of living conditions and the health of children in five Roma camps in Italy. *American Journal of Public Health*, 98(11):2035–2041.
- 34. Gil-Robles, A. (2006a). Final report by Mr Alvaro Gil-Robles, Commissioner for Human Rights, on the human rights situation of Roma, Sinti and Travellers in Europe. Strasbourg, Council of Europe (CommDH(2006)1; https://wcd.coe.int/ViewDoc.jsp?id=962605&BackColorInternet=99B5AD&BackColorIntranet=FABF45&BackColorLogged=FFC679).
- 35. The study used maternal education as a marker of socioeconomic status. Controlling for maternal education did not account for the entirety of the association between Roma ethnicity and the diseases indicated. Dostal, M., Topinka, J., and Sram, R.J. (2010). Comparison of the health of Roma and non-Roma children living in the district of Teplice. *International Journal of Public Health*, 55:435–441.
- 36. Rosicova, K., Madarasova Geckova, A., van Dijk, J.P., Kollarova, J., Rosic, M., and Groothoff, J.W. (2010). Regional socioeconomic indicators and ethnicity as predictors of regional infant mortality rate in Slovakia. *International Journal of Public Health*.
- 37. Idzerda, L., Adams, O., Patrick, J., Schrecker, T., and Tugwell, P. (2011). Access to primary healthcare services for the Roma population in Serbia: a secondary data analysis. *BMC International Health and Human Rights*, 18;11(1):10.
- 38. Kosice Office of Public Health. "Roma population living in Slovakia: main characteristics." On file with the author.
- 39. The Bulgarian Law on Protection Against Discrimination established as a protecting body the specialized Committee for Protection Against Discrimination. This Committee has multiple

roles; the Committee should address complaints of discrimination; impose administrative sanctions; conduct trainings; and elaborate reports, recommendations, and surveys.

- 40. Open Society Institute. (2005). Mediating Romani Health. Budapest: Open Society Institute. pp. 6, 7.
- 41. Open Society Institute. (2005). Mediating Romani Health. Budapest: Open Society Institute. pp. 7, 8.
- 42. Open Society Institute. (2005). Mediating Romani Health. Budapest: Open Society Institute. p. 6.
- 43. "Habitual residents" are persons who lack citizenship but who have long lived on the territory of Macedonia.
- 44. Barker, G., Ricardo, C., and Nascimento, M. (2007). Engaging men and boys in changing gender-based inequity in health: evidence from program interventions. Geneva: World Health Organization. (http://www.who.int/gender/documents/Engaging\_men\_boys.pdf, accessed 8 July 2011).
- 45. Jana Kollarova and Frantiska Ondrasikova, Kosice Office of Public Health. March, 2011. Personal communication with the author.
- 46. The first two paragraphs in chapter 6 were written by the study author in OSF's recently published *Beyond Rhetoric: Roma Integration Roadmap for 2020*. The report includes recommendations to the European Commission based on OSF's long record of Roma integration experience. The report can be downloaded at: http://www.romadecade.org/beyond\_rhetoric.
- 47. Jan, S. (1998). A holistic approach to the economic evaluation of health programmes using institutionalist methodology. *Social Science & Medicine*, 47(10):1565–1572; Walker, D.G. and Jan, S. (2005). How do we determine whether community health workers are cost-effective? Some core methodological issues. *Journal of Community Health*, 30(3):221–229.
- 48. Jan, S. (1998). A holistic approach to the economic evaluation of health programmes using institutionalist methodology. *Social Science & Medicine*, 47(10):1565–1572.
- 49. Open Society Foundations. (2010). Decade Watch: results of the 2009 survey. Budapest: Open Society Institute.
- 50. State Statistical Office for the former Yugoslav Republic of Macedonia. (2007). Republic of Macedonia, Multiple Indicator Cluster Survey 2005–2006. Skopje: State Statistical Office.
  - 51. UNDP. (2006). At risk: Roma and the displaced in Southeast Europe. Bratislava: UNDP.
- 52. Loewenberg, S. (2006). The health of Europe's most marginalised populations. Lancet. 368(9553):2115.
- 53. Seguliev, Z. et al. (2007). Current measles outbreak in Serbia: a preliminary report. Eurosurveillance, 12(11) (http://www.eurosurveillance.org/ew/2007/070315.asp#2, accessed 8 July 2011); Orlikova H. et al. (2010). Spotlight on measles 2010: a measles outbreak in a Roma population in

Pulawy, eastern Poland, June to August 2009. Eurosurveillance, 15(17) (http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=19550, accessed 8 July 2011).

- 54. Jana Kollarova and Frantiska Ondrasikova, Kosice Office of Public Health. March, 2011. Personal communication with the author.
- 55. Studiorum. (2011). COPORE—Good practices in poverty reduction: efforts in healthcare. On file with the author.
  - 56. Studiorum. (2011).
- 57. This and other reports from the National Network of Health Mediators in Bulgaria can be found at: www.zdravenmediator.net.
  - 58. See: http://vimeo.com/26663307 or http://www.youtube.com/watch?v=9ktNdrC2Gpg.
- 59. Ministry of Health, Republic of Serbia and OSCE. (2010). The second symposium on female health mediators: proceedings. Brussels: European Union.
- 60. Ministry of Health, Republic of Serbia and OSCE. (2010). The second symposium on female health mediators: proceedings. Brussels: European Union.
- 61. O'Higgins, N. and Ivanov, A. (2006). Education and employment opportunities for the Roma. Comparative Economic Studies. 48(6–19).
- 62. Bodewig, C. and Kurckova, L. (2009). Enhancing the employment chances of Roma. Europe and Central Asia Knowledge Brief. March 2009, Volume 2. (http://ceu.academia.edu/LuciaKurekova/Papers/302862/Enhancing\_the\_Employment\_Chances\_of\_Roma.\_Knowledge\_Brief, accessed 11 July 2011).
- 63. O'Higgins, N. and Ivanov, A. (2006). Education and employment opportunities for the Roma. Comparative Economic Studies. 48(6—19).
- 64. Bodewig, C. and Kurckova, L. (2009). Enhancing the employment chances of Roma. Europe and Central Asia Knowledge Brief. March 2009, Volume 2. (http://ceu.academia.edu/LuciaKurekova/Papers/302862/Enhancing\_the\_Employment\_Chances\_of\_Roma.\_Knowledge\_Brief, accessed 11 July 2011).
- 65. Cohen, J., Gabriel, B. and Terrell, C. (2002). The case for diversity in the healthcare workforce. Health Affairs, 21(5):90–102.
- 66. Lehmann, U. and Sanders, D. (2007). Community health workers: what do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers. Geneva: World Health Organization. (http://www.who.int/hrh/documents/community\_health\_workers.pdf, accessed 12 July 2012).
- 67. Lehmann, U. and Sanders, D. (2007). Community health workers: what do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers. Geneva: World Health Organization. (http://www.who.int/hrh/documents/community\_health\_workers.pdf, accessed 12 July 2012).

- 68. Schaaf, M. (2007). Confronting a hidden disease: TB in Roma communities. Budapest: Open Society Institute.
- 69. World Health Organization European Region. (2009). Health in times of global economic crisis: implications for the European Region. EUR/RC59/R3. (http://www.euro.who.int/\_\_data/assets/pdf\_file/0005/68945/RC59\_eres03.pdf, accessed 13 July 2011).
- 70. Ciobanu, C. (2010). Amid budget cuts, hundreds of Romanian children have lost their homes this year because their foster parents can no longer afford their upkeep. Independent Living Institute. (http://www.independentliving.org/docs10/Budget-Cuts-Romania.html, accessed 13 July 2011); Dărăbuş, S. (2011). Posts are blocked in the childcare system. Child Protection. (http://www.protectiecopii.ro/2011/04/posts-are-blocked-in-the-childcare-system/, accessed 13 July 2011).
- 71. Dinkic, M., Ognjenovic, K., and McClelland, S. (2009). Impact analysis of the health policies on the accessibility of healthcare for the Roma population in Serbia. Belgrade: Oxford Policy Management. (http://www.inkluzija.gov.rs/wp-content/uploads/2010/03/Impact-Analysis-of-the-Health-Policies-on-the-Healthcare-of-the-Roma-Population.pdf, accessed 14 July 2011).
- 72. Commission on the Social Determinants of Health. (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Geneva: World Health Organization. (http://www.who.int/social\_determinants/thecommission/finalreport/en/index.html, accessed 14 July 2011).
- 73. Reports from the 2006 to 2008 phase of the PHARE project can be found on the webpage of CEEN Economic Project and Policy Consulting at: http://www.roma.ceen-consulting.com. Other PHARE project reports can be found on the Network of Health Mediators website, at: www.zdraven-mediator.net.
  - 74. Ibid.
- 75. Scheffel, D.Z. (2004). Slovak Roma on the threshold of Europe. *Anthropology Today*, 20(1):6–11.
- 76. UNHCR. (2011). 2011 Regional operations profile: south-eastern Europe. (http://www.unhcr. org/pages/49e48d8f6.html, accessed 19 July 2011).
- 77. See: http://www.promundo.org.br/en/news/launch-of-the-global-toolkit-for-action-on-engaging-men-and-boys-in-gender-equality-and-health/.
- 78. All of these benefits are measurable. Unfortunately, countries have not and continue to not collect the data required to measure almost all of them.

#### **Open Society Foundations**

The Open Society Foundations work to build vibrant and tolerant democracies whose governments are accountable to their citizens. Working with local communities in more than 70 countries, the Open Society Foundations support justice and human rights, freedom of expression, and access to public health and education.

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### Public Health Program

The Open Society Public Health Program aims to build societies committed to inclusion, human rights, and justice, in which health-related laws, policies, and practices are evidence-based and reflect these values. The program works to advance the health and human rights of marginalized people by building the capacity of civil society leaders and organizations, and by advocating for greater accountability and transparency in health policy and practice. The Public Health Program engages in five core strategies to advance its mission and goals: grantmaking, capacity building, advocacy, strategic convening, and mobilizing and leveraging funding. The Public Health Program works in Central and Eastern Europe, Southern and Eastern Africa, Southeast Asia, and China.

www.soros.org/initiatives/health

#### Roma Health Project

The Roma Health Project, part of the Open Society Public Health Program, works to advance the health and human rights of Roma persons. The project focuses mainly on grantmaking and advocacy efforts, including strengthening the capacity of Roma organizations and activists. In order to achieve its mission, the Roma Health Project works to promote the human rights of Roma and combat discrimination in accessing health care; support the development and implementation of policies that ensure health equity for Roma; and hold authorities accountable for their responsibilities to Roma under local, regional, national, and international laws and policies. The project works primarily in Bulgaria, Macedonia, Romania, Serbia, Slovakia, and to a lesser extent, Ukraine. It collaborates with regional civil society organizations such as the European Roma Rights Center, Romani CRISS, and other Open Society programs.

Roma Health Mediators: Successes and Challenges looks at mediation programs in six countries: Bulgaria, Macedonia, Romania, Serbia, Slovakia, and Ukraine. Mediators have made great strides in addressing the poor health conditions found in Roma settlements in these countries. They have helped increase vaccination rates among Roma, helped clients obtain identification and insurance documents, provided health education to Roma children and adults, and improved health care provider knowledge and attitudes about Roma.

Despite the success of such programs, Roma Health Mediators remain plagued by several challenges. Mediators tend to earn low salaries and have limited professional development opportunities; at the same time, they lack adequate supervision and support. Some mediation programs have inconsistent financing, resulting in contract insecurity for mediators. Moreover, mediators are often isolated from other parts of the health care system and some countries continue to ignore the social factors that lead to poor health in Roma communities.

