

# Mediating Romani Health

Policy and Program Opportunities



OPEN SOCIETY INSTITUTE  
Network Public Health Program

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—Marta Schaaf





# Executive Summary

The 12 to 15 million Roma<sup>1</sup> living in Western and Eastern Europe exhibit some of the region's worst health indicators.<sup>2</sup> Discrepancies in health between Romani and majority communities reflect serious overall inequalities between the Roma and non-Romani populations.<sup>3</sup> Among Romani populations, unhealthy living conditions are one of the major causes of poor health, particularly in the many ghettoized settlements. The conditions contributing to Romani health problems include sub-standard and crowded housing; little or no access to clean water, infrequent or nonexistent garbage collection, lack of access to roads; and general geographic isolation. Other social issues, such as poverty, discrimination, and low position in the social hierarchy, play an equally important role in shaping Romani health.

One of the most visible elements of government strategies to address Romani health has been the creation of Roma Health Mediator (RHM) programs. Members of the Romani community themselves, RHMs aim to improve community health through: (1) mediating between Romani patients and physicians during medical consultations, (2) communicating with Romani communities on behalf of the public health system, (3) providing basic health education, and, (4) assisting Roma in obtaining the health insurance or identity documents necessary to visit the doctor.

As an increasing number of Eastern European countries plan to initiate or expand RHM programs, the Open Society Institute's (OSI) Network Public Health Program commissioned this study of the Roma health mediator model in Bulgaria, Finland, and Romania. The study

examines various types of health mediator programs and the determinants of Romani health that RHMs can and cannot address.

A team of 12 consultants with expertise in human rights, public health, and/or Romani issues participated in designing or conducting the focus groups, in-depth interviews, extensive literature review, and report writing that is reflected in this study.

The overall goal of the study is to identify the potential and limitations of health mediator programs for addressing the determinants of Romani health. Study activities examined: (1) the history, structure and efficacy of health mediation programs, and, (2) how these programs fit into overall government strategies and actions to address Romani health.

## Findings

The study revealed that RHMs have greatly assisted individual Romani clients. However, 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.

Study activities identified several obstacles to health promotion that Roma health mediation programs should address. Within the Romani community, the following general trends were noted:

- ▶ Perception that health is the absence of biological disease
- ▶ Lack of demand for preventive services

The medical community is generally characterized by:

- ▶ Perception that health is primarily the absence of disease and consequent focus on diseases, particularly infectious diseases
- ▶ Paradigm of individual responsibility, meaning that individual choices, and not social structures, are understood to entirely determine health
- ▶ Lack of focus on increasing patient health knowledge

The negative impact of these trends within the Romani and medical communities can be countered through health promotion, which has been described as “the process of enabling

people to increase control over, and to improve, their health.”<sup>4</sup> To effectively promote health in accordance to these definitions, governments should create avenues for community participation and facilitate individual and community empowerment. Physicians can empower their patients by seeking to increase patient health literacy, which means helping patients to understand health information and services so that they may make appropriate health decisions.

Donors and the EU have attempted to facilitate the adoption of a health promotion approach via the EU accession process and the Decade of Roma Inclusion initiative. Sponsored by governmental and nongovernmental agencies and nine Central and Eastern European governments, the Decade of Roma Inclusion is intended to redress long-standing inequities. Both EU accession and the Decade entail activities and funding in support of Roma health mediation. The Decade gives particular emphasis on the need for governments to create Romani health action plans. However, both the EU accession process and the Decade action plans have been marked by deficiencies for promoting Romani health.

EU monitoring of human rights in candidate countries has been critiqued as being inconsistent, and EU funding mechanisms have been labeled as difficult to access for NGOs. The study team also identified several weaknesses in existing Decade health action plans, including:

- ▶ Little participation by Roma, the Plans’ intended beneficiaries
- ▶ Lack of specificity in activity descriptions and monitoring
- ▶ Poor mainstreaming of the Decade’s cross cutting themes of discrimination, gender, and income poverty

These notable omissions suggest that the plans were developed in isolation from larger health system reform needs, and that governments are not yet willing to address some of the biggest barriers to improved Romani health.

On the level of individual RHM programs, the study team found that mediators effectively address several components of Romani health. 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 seem to 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.

While this work helps to improve the health of Romani individuals, the study team did find a risk posed by mediators continuing to fill a communication gap between clients and

medical providers—both clients and physicians could become dependent on the mediators. Instead of encouraging doctors to adapt a health promotion approach of enhancing patient health literacy, mediation could actually relieve doctors from passing on essential information in a manner that a patient understands. Paradoxically, mediation may serve to increase the distance between patient and doctor, and, unless the mediator 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.

## Conclusions and Recommendations

Policymakers concerned with Romani health should broaden their conceptions of the causes and appropriate remedies for health inequalities between Roma and the overall population. These broadened conceptions should be reflected in: (a) RHM programs; (b) National Action Plans for Romani health; and, (c) national strategies for health reform, social inclusion, minority rights, and women's and youth empowerment. Recommendations thus target three major actors involved in governmental efforts to address vulnerable groups—RHM program implementers, national level policymakers, and donors.

### Recommendations to RHM Program Implementers

1. Undertake participatory evaluations of ongoing programs with the need for program refocus in mind.
2. Re-orient RHM training and role definition to facilitate patient empowerment through health literacy development.
3. Provide training and support to address some of the special needs of doubly marginalized groups.
4. Provide additional professional support to RHMs.
5. Institutionalize mechanisms to capitalize on RHM knowledge.

6. Strengthen mechanisms of supervision and accountability.
7. Increase physician involvement.
8. Provide additional administrative support to RHMs.
9. Publicize the program among the overall population.
10. Increase the number of mediators within the framework of RHM programs newly oriented toward patient health empowerment.

### **Roma Health Strategy and NAP Recommendations for National Policymakers**

1. Improve current health action plans to address the social determinants from a health promotion perspective.
2. Define benchmarks for action plan implementation.
3. Implement all action plan components.
4. Create separate programs to address the issue of documentation.
5. Create multiple links between the Romani community and service providers.
6. Integrate Romani health needs into overall health and social services reform.

### **Recommendations to Donors**

Donors should support any of the above recommended activities as well as the following:

1. Support Decade Action Plan implementation monitoring or evaluation.
2. Build Romani and other NGO capacity in health promotion.
3. Enhance individual capacity for health promotion.
4. Fund legislative or policy audits of health and social assistance laws, and associated advocacy efforts.

5. Fund unique partnerships for legislative and policy audits that examine laws not traditionally considered in Romani health programming.
6. Fund innovative health promotion partnerships to study and address double marginalization.
7. Facilitate information sharing across municipalities.
8. Facilitate information sharing of RHM models.
9. Fund innovative community level programming and document successes.

RHM programs should be refocused to better facilitate individual and community health empowerment, and policymakers should assess and implement complementary legislative reforms and changes to the health and social assistance systems that will decrease the long term need for health mediation. Implementation of comprehensive efforts such as these by participating countries would improve overall health status and health system fairness to the benefit of all citizens, regardless of their ethnicity.

# Introduction

Roma Health Mediators (RHMs)—members of the Romani community who work with their communities, physicians, and national health care systems to improve Romani health—face a daunting challenge as the 12 to 15 million Roma<sup>1</sup> living in Western and Eastern Europe exhibit some of the region’s worst health indicators.<sup>2</sup> Infant mortality rates among Romani communities in the Czech and Slovak Republics and Hungary are about double the national average.<sup>3</sup> A 1997 study in the Czech Republic revealed large discrepancies in infection rates between Roma and non-Roma for a number of diseases.<sup>4</sup> In Serbia, Roma living in ghettoized settlements experience rates of intestinal illness 10 times that of the general population.

Higher rates of illness lead to shorter and more difficult lives for the Roma. Although health data is scarce because morbidity and mortality statistics are often not disaggregated by ethnicity, the available information indicates that life expectancy for Roma throughout Eastern Europe is about 10 years less than that of the overall population.<sup>5</sup> The discrepancies between Romani and majority community health indicators also point to serious inequalities between Romani and non-Romani populations.<sup>6</sup>

Governments in the region have developed RHM programs as a partial response to these grim statistics. As these efforts move forward, they are faced with two important questions: To what extent do these programs effectively confront the conditions causing poor health among Roma? And, to what extent do they, in tandem with other national and international policies, mirror or enable continuing inequity?



This study attempts to answer these questions by examining the effectiveness of RHMs in improving Romani health, and by examining their role in overall governmental efforts to reduce inequalities in access to health care.

Unhealthy living conditions are one of the major causes of poorer health among Romani populations, particularly in the many ghettoized settlements. These conditions include sub-standard and crowded housing; little or no access to clean water, garbage collection, and roads; and geographic isolation. Other social issues, such as poverty, discrimination, and low position in the social hierarchy play an equally important role in shaping Romani health. Experts agree that social, economic, and political conditions influence population health as well as the public health policy that is meant to improve population health.<sup>7</sup>

RHM programs are meant to respond to these conditions by selecting individuals from Romani communities to work as mediators who: (1) facilitate communication between Romani patients and physicians during medical consultations, (2) communicate with Romani communities on behalf of the public health system, (3) provide basic health education, and, (4) assist Roma in obtaining the health insurance or identity documents necessary to visit the doctor.

Romani health mediation is a key element of the many National Action Plans (NAPs) that Eastern European governments have developed as part of European integration or the recently launched Decade of Roma Inclusion. Intended to redress longstanding inequities, the Decade was initiated by nine governments and several key international governmental and nongovernmental agencies. In addition to its prominence in NAPs, Romani health mediation is often noted as a best practice or example intervention by international agencies assessing Romani health, including the Council of Europe (CoE), the European Monitoring Center on Racism and Xenophobia, the European Commission, and the Organization for Security and Cooperation in Europe (OSCE).<sup>8</sup> Governments of implementing countries often tout the mediator program as one of the few tangible actions they have taken in the field of Romani health. Yet mediator programs in implementing countries have apparently never been independently evaluated.<sup>9</sup>

As an increasing number of Eastern European countries are planning on initiating or expanding RHM programs, the Open Society Institute's Network Public Health Program commissioned this study of the Romani health mediator model in Bulgaria, Finland and Romania. The study examines various types of health mediator programs and the determinants of Romani health that mediators can address as well as those they cannot. To encourage holistic approaches to improving health, the analysis considers broader policy developments in human rights and public health. The resulting recommendations invite national and local authorities to discuss realistic expectations for health mediation and for other legislation, policies, and programs required to improve Romani health. Program planners, donors, and Romani rights advocates should also find these recommendations practical as they pursue advocacy, support, and implementation of initiatives addressing Romani health.

National authorities interviewed agree that mediator programs are temporary measures that should be implemented as part of a continuum of reforms intended to decrease the health inequalities between Romani and majority populations.<sup>10</sup> The focus groups, in-depth interviews, and extensive literature review conducted as part of this study revealed that RHMs have greatly assisted individual Romani clients. However, program results have not been effectively leveraged to affect 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; they are not accompanied by necessary legislative changes, nor are they adequately integrated into the overall public health system.

This report recommends that RHM programs should be refocused to better facilitate individual and community health empowerment, and policymakers should assess and implement complementary legislative reforms and health and social assistance system changes that will decrease the long term need for health mediation. These efforts should be coordinated with broader initiatives to decrease socio-economic inequalities.

## Methodology

The overall goal of this study was to identify the potential and limitations of health mediator programs for addressing the determinants of Romani health. The study examined: (1) the history, structure and efficacy of health mediation programs, and, (2) how these programs fit into overall governmental strategies and actions to address Romani health.

The study focuses on Romani health mediator programs in three countries—Bulgaria, Finland, and Romania. Some information relating to a Romani health education program in Kosovo was gathered as well. Countries were selected based on their collective representation of the diversity of mediator programs. Insofar as possible, urban and rural areas were visited in each country.<sup>11</sup>

The programs visited in Finland and Kosovo are not health mediation *per se*. Finnish mediators facilitate communication between the Romani community and government entities in general, including education, social assistance, housing, medical, and legal authorities. The project in Kosovo entailed the training of Romani peer health educators, who conduct community health education seminars and who have attempted to mediate between patients and doctors. The study was undertaken in Finland and Kosovo to illuminate our understanding of mediator programs generally and to explore alternative means of mediation and health promotion.<sup>12</sup>

The primary components of the study included:

▶ **Literature Review**

An academic and gray literature review was undertaken of intercultural mediation; Romani health; Romani rights in Europe; international governmental organization statements/programs in Romani health; governmental strategies addressing Roma; participatory health program planning and evaluation; and the social determinants of health.

▶ **Qualitative Field Assessment in Bulgaria, Finland, and Romania**

At least three study team members conducted the assessment in each country. All team members had substantial experience in Romani health and in working in Romani communities. Two of the three team members in Finland and Romania and two of the four in Bulgaria were Roma. The assessment broadly included roundtables with RHMs, RHM clients, and health providers;<sup>13</sup> surveys of RHMs and RHM clients;<sup>14</sup> and interviews with governmental and nongovernmental stakeholders.<sup>15</sup>

▶ **Interviews with other Stakeholders**

Other stakeholders included representatives of the CoE, Romani activists working elsewhere in Eastern Europe, and governmental representatives addressing Romani health elsewhere in Eastern Europe.

Both the methodology and the final report were critiqued by several Romani health experts<sup>16</sup> and activists.

## **Biases**

The field assessment was biased in that all RHMs, clients, and health providers who were interviewed came forward voluntarily. While in most cases all of the RHMs working in a particular catchment area were interviewed, the clients likely do not represent a statistically significant portion of those served in a given location. The client surveys were thus analyzed as qualitative, rather than quantitative data. Moreover, the RHMs have an interest in ensuring that the program employing them continues, and may have been reluctant to share information or opinions they feared would endanger program continuation.

In order to correspond to the study objectives of exploring RHM program implementation and overall Romani health strategy, the findings are split into 3 categories: Chapter 1 examines RHM program structure, Chapter 2 provides an overview of the Romani health conceptual and policy context, and Chapters 3 and 4 assess RHM program effectiveness.

# 1. Mediation Programs in Finland, Romania, and Bulgaria

## Background

Mediation aims to resolve a conflict between two parties, and can be defined as “assisted communications for agreement.”<sup>1</sup> So-called intercultural mediation was developed to facilitate minority population communication with public authorities and systems providing health, social, legal, and education services. Intercultural mediation with the Romani community was first used in France in 1986, as part of a program to relieve tensions between social workers and the Romani community.<sup>2</sup>

### **Finland**

Approximately 10,000 Roma live in Finland,<sup>3</sup> comprising about 0.2 percent of the total population.<sup>4</sup> An additional 3,000 Finnish Roma live in Sweden.<sup>5</sup> Other minority groups in Finland include Finnish Swedes, Russians, Estonians, and Sami, an indigenous population. Finnish Swedes are the largest minority, comprising about 5.7 percent of Finland’s total population.<sup>6</sup>

The Finnish government pursued a policy of Romani assimilation from the 1900s to the 1960s, and only in the 1970s began to support the maintenance of the Romani culture and social inclusion.<sup>7</sup> Government assistance to Romani intercultural mediation reflects this later multicultural/integrationist orientation.

Romani mediation was formalized in Finland in 1993, when Ryhdys, the Finnish professional association of Romani mediators, was registered as a nongovernmental organization. Members were Romani individuals who had been acting informally as liaisons between the Romani community and Finnish authorities. Following the formalization of Ryhdys, the director of the organization elaborated mediator qualifications and selected additional mediators according to consensus at open community meetings. Municipal authorities appreciated the contributions of the mediators, but were not willing to use municipal funds to pay them. Mediators thus worked voluntarily.<sup>8</sup> However, governmental entities did provide some support; the Helsinki Office for Social Services donated office space and equipment to Ryhdys, and the Ministry of Labor paid most of a secretary's salary until 2002.<sup>9</sup>

The Romany Education Unit was founded within the Finnish National Board of Education in 1994, with one of its tasks being the training of Romani mediators.<sup>10</sup> The unit is financed with adult education funds from the national budget, and is operated by a management group with Romani representation. From 1995 to 2000, staff provided weekend-long seminars to mediators covering Finnish citizenship, social care and services, health care and services, child care, social insurance, the Finnish educational system, and unemployment assistance. As these seminars were only two days long and given only twice a year, Ryhdys members began to request a more formalized training and professional designation.<sup>11</sup>

From 2001 to 2004, the Romany Education Unit, in partnership with Ryhdys and governmental agencies and Romani NGOs in Estonia, France, Great Britain, Denmark, Lithuania, and Sweden implemented the Drom-Edu Roma mediation project. Drom-Edu was funded by the European Union's Socrates Comenius program, which, among other things, aims to promote intercultural awareness in school education in Europe.<sup>12</sup> The goal of the program was to facilitate the integration of Romani children by training mediators to work as a contact between home and school, increasing teacher awareness of Romani culture and the needs of Romani children, explaining the history and culture of Roma living in each country to majority and minority ethnicity children in partner countries, and compiling and disseminating best practices.<sup>13</sup>

While the Drom-Edu program goal addressed only education, the training and functioning of the mediators extended beyond education issues. The training seminars provided to Finnish mediators totaled 18 days, and covered topics such as Finnish citizenship, social care and services, health care and services, child care, social insurance, substance abuse, the educational system, unemployment, pertinent EU organizations, hobbies and leisure time activities, Roma in Finland, and discrimination. Mid-training and final exams were administered.<sup>14</sup> The 21 participants also received training in basic computer skills.

According to their job descriptions, mediators are expected to carry out the following tasks: examine the living conditions of the Romani population and the problems caused by societal structure and the living environment; act as a source of information for the majority population; advocate for Roma in various sectors of society; plan and coordinate vocational and recreational training and activities with authorities and associations; liaise with congregations, schools, and other communities to promote understanding between the Roma and the majority population; and arrange briefings on Romani issues to various authorities. The Roma Education Unit publicized the program through print and radio advertising and by informing stakeholder agencies such as school boards.<sup>15</sup>

At present, roughly 10 mediators from the Drom-Edu program are still working in some capacity, mostly voluntarily. One is employed by the municipality in the town of Imatra, and another works for the Provincial Board on Romani Affairs (to be discussed below). However, these mediators are no longer supported by Ryhdys, which ended its involvement in 2004.<sup>16</sup> Some mediators who work voluntarily are professionally and logistically supported by a national Finnish Roma association, while others work with no support.

Apart from those mediators affiliated with Ryhdys, Finland has several national or local governmental entities whose function is to mediate between the Romani community and the Finnish government. The Ministry of Social Affairs and Health established a National Advisory Board on Roma Affairs in 1956. Fifty percent of Board members are governmental employees, and 50 percent are Romani organization representatives. The board's major duties include reporting to national authorities on the social and living conditions of Roma; undertaking initiatives to improve the economic, educational, social, and cultural conditions and employment of Roma; working to end all forms of discrimination; furthering Romani culture; and participating in international activities.<sup>17</sup>

In addition to the National Advisory Board, there are also four Provincial Boards on Romani Affairs, which provide mediation services to individual members of the Romani community as well as to governmental agencies and services. The boards' four permanent staff address Romani community member problems relating to housing, employment, and education, among other topics. Mediation is either provided over the phone or on site. The boards also provide lectures and seminars about Romani culture to police academies, housing secretaries, foster care staff, adolescent psychiatrists, the Association of Finnish Local and Regional Authorities, employment offices, high schools, and hospitals. Approximately 80 lectures are delivered per year, and some participants are required to attend by their employers, while others attend voluntarily.<sup>18</sup>

As part of their efforts to create a cadre of professionals capable of providing mediation services and seminars on Romani culture, Finland has recently initiated a technical university certificate for "Cultural Instructors on Romani Culture." One of the graduates from the first class (2004) is employed by a municipality as a mediator.<sup>19</sup>

Finally, various entities within the Finnish government as well as NGOs have prepared manuals for agencies and organizations working with the Roma. These manuals are in keeping with the goals of mediation, as they seek to improve provider understanding of Romani culture and needs. The Ministry of Environment has created a guide for housing authorities;<sup>20</sup> the NGO Romano Missio has developed a manual for service providers addressing drug use;<sup>21</sup> and the National Board of Education created a guide for health care professionals that outlines the history and culture of the Finnish Roma and describes the rationale for various Romani concerns or behavior that may confuse service providers. The authors suggest that health care providers modify their practice or rules to accommodate Romani cultural mores, such as being prepared to accept hospital visits from many family members. They also provide concrete ways of reconciling health care system needs and expectations with Romani cultural needs and expectations. For example, a Romani patient may wish to discuss the illnesses of several family members during an appointment with a doctor. The authors suggest that doctors either inform the patient when she makes an appointment that only the patient's health care concerns can be discussed, or, schedule a longer appointment.<sup>22</sup> The guide has been disseminated widely among Finnish health care staff, as well as internationally as a best practice example.

## Conclusions

Although the Finnish mediation system differs from the programs in Romania and Bulgaria, there is much that these states and others could learn from the Finnish approach to mediation and to addressing Romani exclusion more generally. Finland has greater financial resources than Romania and Bulgaria, but also a notable commitment at the national and local levels to Romani mediation programs. Re-orienting the approach of current programming does not necessarily require greater financial input, although all European countries should increase the amount of funds dedicated to lessening social inequities. Finnish governmental policy reflects an understanding that continued socio-economic exclusion of the Roma is due in large part to: (1) past and present discrimination, (2) past suppression of Romani culture and programs to force assimilation (3) poor awareness of Romani culture among service providers, and (4) past social transitions that undermined the traditional Romani way of life. Finnish mediation programs and activities seek to address the first three factors. For instance, the various Romani advisory boards and the program for instructors in Romani culture ensure Romani participation in public life, offer employment opportunities for Roma, facilitate the maintenance of Romani culture and language, and provide experts who can increase majority population awareness of Romani culture and the effects of discrimination. The institutionalization of these programs reflects widespread policymaker consensus on the need to involve Roma in policymaking and the necessity of addressing service providers as key players in continued disparities between Roma and the overall Finnish population.<sup>23</sup>

Romani involvement in policymaking is less institutionalized in Eastern Europe, and governments often fail to address service providers and structures as a cause of Romani mar-

ginalization. Moreover, RHM and other programs addressing Romani exclusion are often the result of efforts by a few dedicated activists and policymakers, as opposed to reflections of policymaker consensus.

## Romania

About 2.5 million Roma live in Romania,<sup>24</sup> comprising 11 percent of the total population.<sup>25</sup> Hungarian, Russian, German, Ukrainian, and Turkish minorities also live in Romania, but Roma comprise the largest ethnic minority.<sup>26</sup> In 2001, Romania adopted the Strategy of the Government of Romania for Improving the Roma Condition.<sup>27</sup> However, the European Commission<sup>28</sup> has noted that *de facto* discrimination against the Roma is still widespread, and social inequalities between the Roma and other ethnicities are striking.<sup>29</sup>

Intercultural mediation, and health mediation in particular, was started in Romania by the Romani NGO, Romani CRISS (Roma Center for Social Intervention and Studies). In 1997, Doctors Without Borders issued a report alleging that Roma in Romania were refusing vaccination. Romani CRISS investigated, and discovered that physicians refused to enter Romani communities, while Roma were afraid of the effects of vaccination and did not understand its importance. In response, Romani CRISS adapted its intercultural education mediation model to the health context.<sup>30</sup>

The official Romanian mediator job description is long, but the most important elements include fostering mutual trust between local public authorities and Romani communities; facilitating communication between members of the community and medical staff; encouraging pre- and postnatal care; providing family planning information in the community; and encouraging pediatric check-ups, immunization, and nutrition. Mediators are also expected to promote hygiene; facilitate health insurance coverage; mobilize community members to participate in public health campaigns; participate in the detection of TB and other communicable diseases; explain medical prescriptions and treatment in cooperation with the prescribing doctor; and notify social workers about potential school dropouts.

Those nominated as mediators must be women, graduates of primary school, and able to communicate with local authorities as well as their own communities while maintaining the confidentiality of their clients.<sup>31</sup> Program planners elected to employ only women because in Romania, Romani women tend to have primary responsibility for family health. Prevailing Romani culture would not allow male mediators to discuss taboo sexual topics with women. Furthermore, planners felt that hiring female mediators would empower them as women and undermine prevailing perceptions about appropriate women's roles. Romani CRISS strategically chose general practitioners (GP) who were willing to work with RHMs, and used these examples of cooperation to lobby the Ministry of Family and Health to institutionalize the role of RHMs.<sup>32</sup> For its part, the ministry surveyed county public health directorates to ascertain their views regarding the most important causes of public health problems relating to the Romani population. The authorities responded



that the most significant difficulty was communicating with the Romani community.<sup>33</sup> In August 2002, the Ministry of Family and Health passed an ordinance making Roma Health Mediator an official profession within the Romanian public health system.<sup>34</sup>

According to the ministry's ordinance, all mediators must be trained and certified by Romani CRISS. The Romani CRISS theoretical training covers communication, access to prevention and treatment services, the public health insurance system, and first aid. However, RHMs must not provide any medical services,<sup>35</sup> as they are not qualified medical providers. In addition to the standard curriculum, a small percentage of the mediators have also been trained by Romani CRISS to address discrimination.<sup>36</sup> The training structure is somewhat flexible, and training in a long distance format is possible.<sup>37</sup> Graduates of the theoretical training must complete a three month on the job apprenticeship with a "qualified medical staff[person]."<sup>38</sup>

In 2002, the Ministry of Health and Family asked county public health departments and Romani organizations to send their suggestions regarding whether or not mediation was required, how many mediators were needed, and nominations for who should fill this role.<sup>39</sup> If the county department of public health did not respond, no mediator was chosen. The local Romani organization consulted was in many cases the local branch of the Roma Social Democrat Party,<sup>40</sup> which reportedly is the most powerful interlocutor from the Romani community with whom the government cooperates.<sup>41</sup>

Approximately 200 RHMs now work throughout Romania. Geographic distribution is based on need as well as local level willingness to participate. RHMs are currently paid almost 3 million lei (about €83) monthly,<sup>42</sup> which is equivalent to a nurse's salary.<sup>43</sup> They are supervised by local and national authorities, as well as informally by Romani CRISS. Each RHM is assigned to a local contact GP, who is based in a nearby health facility. The GP meets weekly with the RHM to discuss tasks completed and any problems. A representative of the Family and Social Assistance Section of the local county public health department has monthly meetings with each mediator to provide additional supervision and any required assistance.<sup>44</sup> The Family and Social Assistance Section should also reimburse RHMs for travel costs associated with their work.<sup>45</sup> In terms of interactions with national agencies, the RHMs have four meetings per year with staff from the Ministry of Health's Department for the Health of Mother and Child, and must respond to an annual ministry questionnaire.<sup>46</sup> A representative of Romani CRISS phones each mediator about every two months to discuss how work is progressing.<sup>47</sup>

Despite the fact that they had been nominated by local authorities, some RHMs had problems being hired following the initial trainings. Moreover, many medical staff and county public health departments did not understand the role of the mediator, and required substantial support from Romani CRISS and the Ministry of Health and Family to cooperate effectively with the RHMs.

## Conclusions

The institutionalization and comparatively large number of RHMs in Romania is largely due to the concerted effort and skill of a small number of health ministry staff, as well as the general high regard for Romani CRISS within the government and the medical community. The hard work of a few government staff people and the competence and reputation of a Romani NGO created an enabling environment for an institutionalized RHM program.

## Bulgaria

Between 600,000 and 750,000 Roma live in Bulgaria,<sup>48</sup> comprising about 9 percent of the total population.<sup>49</sup> Other minority groups include Turks, Macedonians, Armenians, and Tatars. Turks are the largest group, representing 9.4 percent of Bulgaria's total population.<sup>50</sup> From the 1950s to 1990, the Bulgarian government pursued a policy of forced assimilation of all minority groups. For the Roma, this meant forced settlement and Bulgarianization of their names, among other things.<sup>51</sup> Since 1990, the government has made some key legislative changes concerning minority rights. The Framework Programme for Equal Integration of Roma into Bulgarian Society was passed in 1999. A strategy for improving minority, particularly Roma, health has also been developed, and will likely be adopted in the near future.<sup>52</sup> However, the European Commission has observed continuing public expressions of racism; de facto discrimination in access to education, employment, health and social services; and frequent allegations of police violence against Roma.<sup>53</sup> The government has also failed to name an independent Commission for the Prevention of Discrimination, a key element of recently passed antidiscrimination legislation.<sup>54</sup>

In contrast to Romania, Romani health mediation in Bulgaria is not funded or supervised at the national level. It was initiated by the NGO Ethnic Minorities Health Problems Foundation (EMHPF) in 1997. Run primarily by Bulgarian physicians, EMHPF has trained almost all the RHMs formally working in Bulgaria. The fact that mediation has been propelled almost entirely by an NGO as opposed to the government appears to be due to the relative motivation and skill of EMHPF. The NGO's staff are qualified and eager to train and support mediators, and Ministry of Health officials are willing to let an NGO fill this role, rather than trying to identify governmental human and financial resources for these activities. However, the government is becoming more involved as establishing Romani health mediation at the national level is a fundamental element of the ministry's pending strategy on minority health,<sup>55</sup> as well as of the Decade action plan.

The first large scale RHM project in Bulgaria began in 2001 and ended in 2004. Funded by PHARE, an EU funding mechanism, the health component of the Project for the Integration of the Roma Population covered 15 towns and trained 50 RHMs. In order to be chosen as mediators, applicants must have completed secondary school (some medical training was preferable), be accepted by the community, have strong communication skills, and have worked for more than two years on social issues in the Romani community. As opposed to Romania,

where RHM selection was often done by a representative of the local branch of the Roma Party, RHMs candidates in Bulgaria were interviewed by a panel with representatives of the EMHPF, local physicians, the municipality, and the Romani community.<sup>56</sup> Also, 30 nurses and 30 GPs were trained to work with RHMs. To provide incentives for cooperation, the Ministry of Health provided needed medical equipment to 15 participating primary health care centers.

The RHM job description names the following tasks: accompanying Roma to health care or social assistance institutions, facilitating communication during visits to the doctor, lobbying health care institutions, protecting patient's rights, reporting violations and acts of discrimination, assisting Roma in navigating bureaucracy, explaining to Roma how the health and social assistance systems function, explaining to medical staff and social workers the needs and status of Roma, participating in health prevention programs, providing health education, supporting young mothers, communicating with local and regional authorities regarding the health status of the Roma, conducting reproductive health activities, assisting local sanitary and hygiene inspections, and offering psychological support to families of people suffering from chronic diseases or disabilities.<sup>57</sup> The tasks enumerated in the Bulgarian RHM job description emphasize patient's rights and reporting discrimination more than RHM job descriptions in Romania and Finland. Yet the extent to which this difference translates into actual increased attention to patient's rights seemed to be minimal. No RHM in any country cited these tasks as a regular part of their work.<sup>58</sup>

The mediator training curriculum was developed by the EMHPF, the Open Society Institute–Sofia, the Bulgarian Association for Family Planning and Sexual Health, and the Romani organization Balkan Foundation Diversity. It was approved by the ministry, and included several modules:

1. health and social assistance
2. prevention
3. pertinent health issues: reproductive health, hereditary disorders, and hygiene
4. Identification documents and their role in health assistance
5. communication skills
6. Romani history and culture

The training comprised 15 lectures and cooperation games. Some lectures were for RHMs exclusively, while others were given to RHMs, GPs, and nurses. An exam was administered at the end of the training.<sup>59</sup>

About 10 of the 50 RHMs trained are currently employed. Three are funded by their local municipality, although the longest contract is for one year.<sup>60</sup> The additional two-person teams are supported and supervised by the EMHPF and a local NGO, and funded by the Open Society Institute–Sofia.<sup>61</sup>

Educational and Medical Integration of Vulnerable Groups, a new PHARE project granted to the Bulgarian government, will use contractors hired by the government to implement activities such as the training of 50 additional RHMs, and an undetermined number of GPs and nurses.<sup>62</sup>

### **Conclusions**

Both the Romanian and the Bulgarian programs lack the comprehensive approach of Finland, which explicitly aims to involve Roma at all levels. While Bulgaria does have a more democratic and participatory mediator selection process than Romania, it lacks national policymaker consensus and commitment to Roma health mediation. Local programs are not sustainable in part because there is no national legislation regarding financial support. Moreover, the government appears not to have consulted a cadre of Romani experts and activists (such as those working at Romani CRISS) who can ensure at least some Romani participation at the implementation and policymaking level.



## 2. International Policy Context: The Right to Health, EU Accession, and the Decade of Roma Inclusion

This section lays out key international policy standards and programs pertinent to Romani health. The discussion of the definition of health and health promotion illuminates the social structures that must be addressed to improve Romani health. Conceptual impediments to implementing a health promotion approach are also explained. Analysis of international political and funding mechanisms shows the extent to which these mechanisms have been effectively or ineffectively leveraged to address social structures and conceptual obstacles to health promotion that underlie poor Romani health.

### Defining Health

What constitutes health? What problems should governmental programs address to effectively improve health?

The World Health Organization (WHO) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”<sup>1</sup> The right to health is enshrined in international law in several treaties, the most important of which is the International Covenant on Economic, Social, and Cultural Rights. The committee charged with monitoring the implementation of the Covenant has articulated “interrelated and essential elements” of the right to health.<sup>2</sup> These elements include:

- ▶ Availability. “Functioning health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity... They will include... the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics, and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries...”
- ▶ Accessibility. This includes nondiscrimination, physical accessibility, economic accessibility, and information accessibility. Information accessibility includes the right to seek and receive information and ideas concerning health issues.
- ▶ Acceptability. “All health facilities, goods and services must be respectful of medical ethics and culturally appropriate...”
- ▶ Quality. Health facilities should be: “scientifically and medically appropriate and of good quality.”<sup>3</sup>

## Social Determinants Shaping Romani Health

Health is not just determined by biology; social conditions play a key role in determining the availability, accessibility, acceptability, and quality of health services and one’s overall health. The importance of social conditions in shaping health as well as continued programmatic failures to confront these structures is now widely acknowledged. In March 2005, the WHO recognized the importance of social determinants to public health policy by forming the Commission on Social Determinants of Health to remedy the fact that “health policies have been dominated by disease-focused solutions that largely ignore the social environment.”<sup>4</sup>

The actual social determinants of health are diffuse, and in the case of poor Roma, often include inequity and discrimination in education and employment; political disenfranchisement; poor access to food; low position in the social hierarchy; poverty and perceptions of relative poverty; lack of control over work and social environments; perceptions of low health efficacy; racism; social exclusion; community instability; unequal gender norms; substandard infrastructure; and poor housing.<sup>5</sup> All of these conditions can affect one’s vulnerability to illness.

The following example starkly illustrates the ways in which social conditions can cause and exacerbate poor health, and limit individuals' capacity to address both health ramifications and the underlying causes. High rates of lead-related illnesses have been discovered among Roma living in an internally displaced persons camp in Kosovo that is in close proximity to a defunct mine.<sup>6</sup> To address the lead poisoning, program planners cannot look only at the physical conditions in the camp. They must consider the almost complete political powerlessness of Roma in Kosovo and the consequent difficulties associated with demanding better housing, the Roma's vulnerability to racial attacks, and the related challenge of actively looking for alternate accommodation. Planners must also take into account lack of education and knowledge among Roma about how to obtain alternate housing or how to minimize lead intake, their poor access to clean water and thus inability to adequately wash food that may be contaminated with lead, and their inability to pay for the travel and out-of-pocket payments<sup>7</sup> required to get needed medical attention in Serbia. Moreover, because of the perceived low political importance of Roma, neither local authorities nor the United Nations Mission in Kosovo prioritize this problem. Rather than simply treating lead poisoning, effective Romani health programming must empower Roma and impel authorities to question—and ultimately to transform—larger social structures.

## The Value of Health Promotion in Addressing the Social Determinants of Health

Over the past decades, policymakers have developed the concept of health promotion as an inclusive framework for advancing public health. As defined in the Ottawa Charter, the primary WHO document outlining international consensus on health promotion, health promotion is “the process of enabling people to increase control over, and to improve, their health.”<sup>8</sup> Health promotion incorporates the broad WHO definition of health, making it fundamental to confronting the social determinants of health.

Health promotion goes far beyond health education. Promoting health in the community means providing individuals with information, as well as the conceptual tools, confidence, and policy avenues to respond to this information individually and collectively. As the Ottawa Charter for Health Promotion declares, “health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities.”<sup>9</sup> Participation and empowerment, as described below, are key factors in enabling people to increase control over, and to improve, their health.



## 1. Participation

Governments often perceive community participation in policy and program development as a donor-imposed condition that brings few positive results and hinders efficient planning and implementation. As a consequence, participation in designing government programs is often reduced to “tokenism.”<sup>10</sup> Meaningless participation can be a self-fulfilling prophecy, since seeking and subsequently disregarding community input could erode community support for government activities and further reinforce existing power imbalances between health providers and communities.<sup>11</sup> In other cases, governments may claim to have solicited community input by consulting with self-declared community representatives. These representatives may just be the most powerful members of the community, and consulting only with them could reinforce extant power relations while having no appreciable impact on the substantive issues in question. In short, inadequate participation could lead to programs that are irrelevant to actual need or that fail to capitalize on human capabilities and community strengths that already exist within the Romani population.

Mechanisms for meaningful participation might include community boards or consultative meetings within communities that occur during policy or program selection, planning, implementation, and evaluation. In developing local level interventions, planners could also employ participatory appraisal techniques, such as focus groups, community mapping of household well-being, gender disaggregated activity calendars, and problem trees.<sup>12</sup> Use of community-wide participatory appraisal techniques will help ensure that some of those in poorest health—the most marginalized—participate as well.

## 2. Individual and Community Empowerment

### Individual Empowerment: Health Literacy and Patient-Centered Communication

Physicians and health care workers are largely responsible for putting into practice two concepts within health promotion that enhance individual agency—health literacy and patient-centered communication. Health literacy can be defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”<sup>13</sup> In a patient/doctor interaction, the physician should provide sufficient information about the health concerns discussed, and should assist the patient in understanding various prevention or treatment options and the implications of each. Health literacy can be improved in part through patient-centered communication, which entails: (1) considering the patient’s needs, wants, and experiences; (2) offering patients opportunities to participate in their own care; and, (3) facilitating cooperation and understanding in the patient/physician relationship.<sup>14</sup>

## Community Empowerment

Individual empowerment and meaningful participatory processes will work in tandem with community empowerment. If, for example, mediator programs are oriented so that mediators and physicians consistently try to improve patient health literacy, and avenues for participation in health programs such as those explained above are provided, individual patients can understand and collectively address the community-level factors determining their health. Avenues for participation should be sensitive to intersecting vulnerabilities. Romani women, Roma with disabilities, Romani sexual minorities, HIV-positive Roma, and others should be empowered as communities to voice their particular needs.

## Conceptual Obstacles to Health Promotion

It is important to highlight some of the most important conceptual obstacles to health promotion within the medical and Romani communities. “Conceptual,” refers to the way health is understood more generally, rather than to the more practical obstacles that limit Romani access to health care, such as poverty and discrimination. These conceptual obstacles include narrow perceptions of health, increasing emphasis on individual responsibility for health, and lack of a patient’s empowerment perspective.

### 1. Conceptual Obstacles within the Romani Community

It must first be said that it is impossible to identify Romani conceptions of health that would be applicable to all communities.<sup>15</sup> Romani communities even within the same city may speak different languages and have differing average levels of income, education, and health care service utilization rates, not to mention cultural norms. Diversity among urban and rural populations and populations in various countries is even greater. Moreover, certain conceptual obstacles are widely shared among populations across Eastern Europe, especially by socio-economically disadvantaged groups. With these caveats in mind, the literature review and the RHM client roundtables revealed the following general trends:

- ▶ *Perception that health is the absence of biological disease.*<sup>16</sup> When asked if they considered themselves to be in good health, RHM clients almost universally responded by stating whether or not they had a diagnosed physical illness. This narrow conception of health may negatively impact biological health outcomes as well as achievement of improved well-being. Biological outcomes may be compromised by failure to complete treatment; as symptoms disappear after taking some medication, a patient may consider herself to be healthy and fail to follow other therapeutic guidelines.<sup>17</sup> Low expectations for physical health and overall well-being are another result; some Roma may feel that poor health is a constant condition rather than changeable.<sup>18</sup> For example, the majority of respondents

to a UNDP survey of Romani settlements in Bulgaria, the Czech Republic, Hungary, Romania, and Slovakia stated that their health and that of their children was “good” or “tolerable.”<sup>19</sup> Given the dire living conditions of respondents, these answers likely reflect poor health literacy and low aspirations for health, rather than actual good health status.<sup>20</sup>

More broadly, a narrow definition of health constrains the imaginations of Romani communities and NGOs in thinking of ways to improve Romani health. Program ideas are often focused on quantifiable biological interventions, as opposed to community health mobilization or policy analysis and lobbying.

- ▶ *Lack of demand for preventive services.* Lack of demand for preventive services stems in part from the perception that health is the absence of disease. Failure to pay adequate attention to prevention results in over-use of costly emergency services<sup>21</sup> and high incidence of preventable illnesses. Assistance is generally sought only in the event of serious sickness. For example, 73 percent of respondents to a UNDP Bulgaria survey stated that they only seek health information when they have a sick relative.<sup>22</sup> These sentiments were echoed by respondents to RHM client surveys in Bulgaria and Romania, who for the most part would first contact a RHM when the need for medical attention was urgent.

As a consequence of these prevailing understandings of health, demand for health mediation is largely confined to assistance in visiting the doctor in the event of illness, or in bio-medical interventions, such as vaccination. Health mediators must work to create demand among their most socio-economically marginalized constituents for preventive health care, health education, and community health promotion events.

## **2. Conceptual Obstacles within the Medical Community**

As in the case of the discussion of the Romani community, the following points are generalizations and are not meant to imply that these are universally held opinions among the staff at health ministries and health professionals. Nonetheless, to the extent that these obstacles exist, to any significant degree, they are likely to have a highly negative impact on equal access to health for Roma and for Romani participation in improving individual and community health.

- ▶ *Perception that health is primarily the absence of disease and consequent focus on diseases, particularly infectious diseases.* Emphasis on disease, as opposed to wellness, characterizes Eastern European health systems as a whole.<sup>23</sup> However, given the particular socio-economic disadvantage of many Roma, this approach has especially adverse consequences for governmental policies for Romani health.

When asked how they would define success of the RHM program, almost half of the GPs interviewed as well as some ministry representatives first cited higher vaccination rates.<sup>24</sup> While vaccination is indeed important, this response is emblematic of the historical focus of public health on avoiding “contagion,”<sup>25</sup> as opposed to promoting health (which would include increased vaccination rates). Some doctors take an even more radical approach, seemingly believing that the most effective remedies to poor Romani health are forced measures to eradicate disease.<sup>26</sup> Medical providers and policymakers need to move away from blaming individual Roma for poor health and recognize how entrenched socio-economic exclusion limit individual choice and opportunities to improve health.

- ▶ *Paradigm of individual responsibility.* A key feature of economic transition and health reform in many countries has been a shift in the responsibility of health care costs from the state to households.<sup>27</sup> At the same time, demand has increased as populations, particularly the poorest, suffer from deteriorating social assistance programs, poorer nutrition, and adverse changes in lifestyle. Health ministries have limited financial resources, while international donor support has sought primarily to further privatize health care.<sup>28</sup> This paradigm shift has been especially difficult for all poor populations, including Roma, who have high expectations of state paternalism. Such expectations are likely due in part to past and ongoing exclusion from mainstream services, resources, and opportunities. Poor access and sustained marginalization restrict many Roma to reliance on state assistance.

In keeping with the growing emphasis on individual responsibility, many of the few government programs that do exist to improve Romani health focus on individual behaviors and health, without addressing the equally important need of community capacity to take action based on new health knowledge.<sup>29</sup> Individual knowledge changes are less effective if individuals concerned are unable to act on their improved knowledge as a result of socio-economic and other constraints. Communities must be collectively supported to identify and redress causes of ill health.

- ▶ *Lack of patient empowerment perspective.* Physicians in Eastern Europe generally do not perceive patients as rights holders, but rather as beneficiaries of the service provided. This stems in part from the entrenched power of the physician community,<sup>30</sup> as well as the legacy of an almost complete lack of a patient’s rights culture during the communist period. Condescending attitudes on the part of doctors are likely exacerbated in cases where clients are uneducated and less likely/able to advocate for themselves or to articulately explain their needs. As a result, physicians generally do not seek to improve patient health literacy, but only to diagnose the illness and prescribe curative care. This perspective is manifest in attitudes toward mediation. When asked to describe the role

of the RHM, the majority of physicians interviewed in Bulgaria replied that the RHM's primary task was to help physicians.<sup>31</sup> Since physicians generally understand the role of the RHM as facilitating the doctor/patient interaction according to the doctor's wishes, then mediators and physicians may not cooperate effectively in improving patient health literacy.

Program design can exacerbate this disproportionate focus on physician, rather than patient needs. As part of their discussions about a large RHM project currently being designed, the Bulgarian Ministry of Health proposes, among other options, that GPs pay RHMs from their pockets or pay them with supplementary funds from the Bulgarian Health Insurance Fund. As Bulgarian GPs are compensated by the Health Insurance Fund on a per patient basis, they would be motivated to employ RHMs as a means of recruiting additional patients. The dangers of this model are clear: RHM dependence on the physician; and thus lack of remedy for the patient and RHM in the event the physician is guilty of discrimination, patient's rights violations, or abuse of the RHM. The RHM would not actually be doing mediation, but would assist a physician with activities that may or may not be in the interest of the client or the Romani community as a whole.

Donors and the EU have attempted to facilitate the adoption of a health promotion approach, and have encouraged greater attention to minority rights, social exclusion, and the particularly dire situation of Roma via two major processes: EU accession and the Decade of Roma Inclusion.

## EU Accession

The EU expanded in May 2004 to include four Eastern European countries with large Romani populations,<sup>32</sup>—the Czech Republic, Hungary, Poland, and Slovakia. Bulgaria and Romania are formal candidates and are expected to join in 2007, and Croatia, also a candidate, will join in 2007 or 2009. Albania, Bosnia and Herzegovina, FYR of Macedonia, and Serbia and Montenegro, which also have substantial Romani populations, seek to become candidates for accession. The process of EU accession or membership provides much of the minority rights conditionality and funding that supports Romani health and integration projects.

### 1. EU Accession and Minority Rights

Joining the EU entails demonstrating respect for minority rights.<sup>33</sup> Candidate country negotiations with the EU focus on fulfilling the three "Copenhagen Criteria," the first of which is to "be a stable democracy, respecting human rights, the rule of law, and the protection of minorities." The European Commission regularly looks at the existence and adoption of policy

measures in determining whether or not a candidate country is meeting its obligation to respect and enhance Romani rights.

### **EU Minority Rights Conditionality: Improvisation and Inconsistency<sup>34</sup>**

A London School of Economics study of EU conditionality and candidate country improvements in minority rights protections concluded that “the Roma issue is the most indicative of the limitations of the EU’s [minority rights] monitoring mechanism.”<sup>35</sup> The European Commission does not specify benchmarks for what constitutes fulfillment of respect for the right to health or minority rights. While the development of strategies is noted as signifying progress toward fulfilling the Copenhagen Criteria, implementation is unevenly accessed. For example, the 1999 European Commission Report on Bulgaria states that the government made “significant progress” in integrating the Roma through the “adoption of a Framework Program for ‘Full Integration of the Roma Population into the Bulgarian Society.’”<sup>36</sup> While the formal step of adopting the strategy has occurred, substantive implementation, and thus substantive improvements in Romani status, has not. National politicians admit to this trend, with the Romanian prime minister stating in 2002 that “The Strategy [for Improving the Roma Condition] is excellent, we adopted it, everybody was satisfied and after that we put it in the drawer.”<sup>37</sup> This disproportionate stress on formal measures is reflected in national government “compliance” with EU requirements. In keeping with EU antiracism legislation requirements, Romania has created a National Council for Combating Discrimination. The council is now functional, but it has been criticized for slowness, improper infrastructure, poor staff training, difficult collaboration with other public institutions, inadequate investigatory capacity, and lack of visibility and transparency.<sup>38</sup>

This paper began with a question regarding the extent to which Eastern European government policies vis-à-vis Romani rights mirror or seek to undermine the societal inequities shaping Romani health. The extent to which policies continue to reflect societal inequities is due in part to inequitable priorities and resource allocation within the European Commission and member states themselves. Roma are not highly politically salient in the EU. They have little political and economic power and no “backer state” as other Eastern European minorities do. The result is that other EU political concerns generally trump Romani rights concerns. Indeed, a European Commission spokesman on Enlargement explained that “it [the status of Roma] is a problem, but it has not decisively influenced our decision on the readiness of candidate countries to join the EU.”<sup>39</sup>

### **EU Accession and Social Inclusion Funding: PHARE, CARDS, and the European Social Fund**

EU candidates, Albania, and countries of the former Yugoslavia are eligible to apply for pre-accession assistance from the EU in the form of PHARE or CARDS<sup>40</sup> funds, and member states are eligible to receive money from the European Social Fund (ESF). These funds, which

must be co-financed by the candidate country government, have been used to support Romani health mediation development in Bulgaria, and will fund future work in this area in Bulgaria and Slovakia.<sup>41</sup> The EQUAL Initiative, a constituent program of ESF, seeks to disseminate best practices and to facilitate subsequent project scale-up.<sup>42</sup> The EQUAL Initiative has been used to fund Romani health mediation, and intercultural mediation more generally, throughout Western and Eastern Europe.<sup>43</sup> The Czech Republic plans to use ESF to fund its planned health mediation program.<sup>44</sup>

### **Difficulties in Accessing and Sharing Information**

The European Commission has acknowledged a widespread belief that EU funding mechanisms are “fragmented, complex, and... very difficult to access particularly for civil society actors.”<sup>45</sup> Moreover, some critics allege that funding is often granted to “favorite” NGOs with which PHARE staff are already familiar.<sup>46</sup> At the same time, lack of Romani NGO capacity is often cited as the reason for their lack of inclusion in Romani health program design and implementation. Thus, the very tools that could increase Romani NGO capacity are unreachable. Governments mimic this rationale by using lack of Romani capacity as an excuse for failing to allow meaningful participation. As a result, Romani NGOs may be minimally involved in RHM programs, or, donors and governments support the same Romani NGOs which have demonstrated capacity to meet EU requirements. Health mediators generally do not have previous experience in health programming or community activism, so health mediator programs have great potential to overcome this capacity building gap and create new constituencies of Romani health specialists and activists. Governments and donors should capitalize on this opportunity and alter existing programs to broaden Romani NGO participation.

As a major donor to RHM programs in Eastern Europe, the EU has a responsibility to document and share lessons learned regarding program successes and failures. Indeed, this is an explicit objective of the EQUAL initiative. However, the coordinator for the Finnish Drom-Edu Project indicated that this multicountry project was not followed up in any way.<sup>47</sup> Sharing and institutionalizing lessons learned should be even more straightforward in Bulgaria, as PHARE funded the first RHM program as well as the upcoming Educational and Medical Integration of Vulnerable Groups project. However, the pertinent PHARE official in Bulgaria did not reply to emailed questions regarding how PHARE had integrated lessons learned about sustainability and participation. Instead of creating tools and resources to build capacity in a sustainable and cost effective way, EU funding and lessons learned are not available to communities with the least capacity—the same groups that require the most assistance.

### **EU and Health Promotion**

EU Health Promotion policy is less known and funded than human rights policy, but it could be a useful tool to program planners and advocates. In 2002, the EU adopted the Programme of Community Action in the Field of Public Health.<sup>48</sup> Aiming to “contribute toward the attain-

ment of a high level of physical and mental health and well-being and greater equality in health matters throughout the Community,”<sup>49</sup> the program identifies three main strands of action, including promoting health and preventing disease “through addressing health determinants across all policies and activities.”<sup>50</sup> Member states and accession candidates may seek funds from the program to fund health promotion activities.<sup>51</sup> The program could be a funding source to pilot inventive programs to improve Romani health. For example, it is currently funding a multicountry project addressing substance use among Romani communities in Western Europe, as well as a multicountry project developing innovative ways to foster social inclusion of marginalized groups.<sup>52</sup>

## Decade of Roma Inclusion

The Decade of Roma Inclusion is distinct from the process of EU accession. It was launched as an effort to focus donor funds on Romani issues in particular, in part because the process of EU accession did not prove to result in substantial improvements in Romani status. The Decade was formed to address inequities in health as well as in other sectors, and is sponsored by governments, the World Bank, the Open Society Institute, the United Nations Development Program (UNDP), the Council of Europe (CoE), the Council of Europe Development Bank, the Organization for Security and Cooperation in Europe (OSCE), and the European Commission. In February 2005, the Decade was launched in eight Eastern European countries: Bulgaria, Croatia, the Czech Republic, Hungary, FYR of Macedonia, Romania, Serbia and Montenegro, and Slovakia.

A steering committee for the Decade identified four focus areas: (1) education, (2) employment, (3) health, and (4) housing. To ensure adequate attention to disparities that underlie the focus areas, the committee also named three cross-cutting themes: (1) income poverty, (2) discrimination, and (3) gender. Participating governments have voluntarily committed themselves to improving the status of Roma with regard to these priorities. To that end, each government has developed a National Action Plan (NAP) for the respective focus areas.

The health portion of the NAPs of several Decade countries includes the expansion or initiation of RHM programs. According to draft<sup>53</sup> NAPs, Bulgaria, the Czech Republic, Romania, Slovakia, and Serbia will initiate or expand RHM programs. Worryingly, health mediation is often the primary component of governmental strategy to address Romani health. In the Czech Republic, Romani health mediation is the *only* activity foreseen in the country’s health action plan,<sup>54</sup> and in Slovakia, 85 percent of the funds allocated to the health action plan in 2005 will be for its health assistants [mediator] program.<sup>55</sup>

### 1. Necessary Action Plan Components for the Decade of Roma Inclusion

Keeping in mind the challenges and opportunities presented by the international policy context, the social determinants of Romani health, and the appropriateness of health promotion



in transforming social conditions, the following components should be present in effective Romani health action plans:

- ▶ Comprehensive assessment of Romani health status.
- ▶ Recognition of the role of ethnic, racial, and social discrimination in limiting access to health both directly and indirectly.<sup>56</sup>
- ▶ Public awareness campaigns within Romani and majority communities to ensure support for programs focusing on Roma.<sup>57</sup>
- ▶ Coordination and supervision of the program, particularly at the local level.
- ▶ Adequate discrimination and patient's rights laws enforced by a specialized body.<sup>58</sup>
- ▶ Romani-specific interministerial cooperation mechanism. This should include mainstreaming Romani health needs into other national strategies, such as health, youth, women, the elderly, the disabled, and rural development; as well as into plans for legislative reform. Information sharing and programmatic links should be created among Decade focus areas.
- ▶ The needs of those subject to double marginalization—Romani women, Romani persons with disabilities, and Romani sexual minorities, among others—should be mainstreamed into Romani health programs. Where necessary, special programs should be created to address these populations.
- ▶ Participatory program design, implementation, and evaluation, including the use of participatory appraisal techniques to ensure that the desires of community members (and not just Romani political parties or NGOs) are considered.
- ▶ Specified and verifiable measures, benchmarks, indicators, monitoring plans, data needs, time frames, and budget sources.

## **2. Shortcomings in the Decade of Roma Inclusion Action Plan**

An exhaustive evaluation of the Decade and other health plans is beyond the scope of this study. However, since RHM programs will in many cases be initiated or continued within the context of these NAPs, it is important to point out that the draft plans fail to meet many of the requirements of a health promotion approach. Romani participation is inadequate; monitoring and supervision are vaguely defined; information sharing and linkages are not foreseen; and especially vulnerable groups are insufficiently addressed.

### **Little Meaningful Participation by Roma**

The OSCE High Commissioner on National Minorities, the Council of Europe, and the European Monitoring Center on Racism and Xenophobia have decried a consistent lack of Romani participation in national policy planning and implementation.<sup>59</sup> This trend has continued in the context of Decade Action Plans. Some NGOs have already made public their disappointment with the general lack of Romani involvement in Decade planning.<sup>60</sup> Civil society representatives consulted in Romania, Bulgaria, and Slovakia declared that Romani participation in the health component of their country's NAP was discouraged or not sufficiently supported. The health action plan in Romania was allegedly drafted entirely by civil servants;<sup>61</sup> the health section in Bulgaria involved one Romani health professional and an almost finalized draft was sent to Romani NGOs,<sup>62</sup> and neither the Czech Republic nor Slovakia initially developed a health action plan. After being pressured to do so, the Slovak government drafted an action plan in consultation with one Romani social worker, and the Czech government, involving no civil society actors, indicated the expansion of its existing health mediation program as the only element of its health action plan.<sup>63</sup> In some cases, reasons for insufficient Romani community involvement included the lack of public health capacity among Romani NGOs.<sup>64</sup> Rather than perpetuating this lack of capacity, however, governments should capitalize on the opportunity provided by the Decade to build health capacity among civil society actors, and perhaps include explicit goals to this end in their action plans.

Inadequate participation can occur even when many Romani NGO representatives are present. In Serbia, for example, Romani NGO participation was high. However, the Ministry of Health sent only one representative, and many of the action plan measures agreed by Romani participants did not enjoy ministry support.<sup>65</sup> As a result, the action plan developed may reflect Romani community priorities, but it has little chance of being implemented. Participation thus did not entail sharing of power and responsibility, because the resulting action plan has little power. Romani representatives participated in the drafting of a document—the action plan—but not in the development of the policies that will actually be implemented.

### **Lack of Specificity in Activity Descriptions and Monitoring**

The health action plans designed by the countries participating in the Decade are ambiguous and often fail to designate authority for implementation. Named objectives may not have a timeframe; the corresponding indicators may be unrelated or unverifiable (such as “level of knowledge in the field of health protection”),<sup>66</sup> and activities may be completely unclear. The relative specificity of each action plan varies (FYR of Macedonia, for example, has sub-headings and more specific activities within each theme) but overall, the plans are imprecise. These weaknesses undercut the viability of activities, and suggest broader failings in political commitment. Ambiguity allows for diffuse responsibility; it is not clear which entity is ultimately responsible for funding or implementing activities. Where programs are carried out,

monitoring, evaluation, and subsequent program restructuring may not occur because roles and responsibilities have not been clearly established. As a result, Romani health programs may be implemented poorly, limiting the sharing of lessons learned or institutionalization. Furthermore, individual programs will be less successful if they are not part of a thought-out action plan that designates responsibility. When developing action plans, governments should hold interministerial cross-sectoral planning sessions and community consultations where implementation responsibility, benchmarks, timelines, and monitoring and evaluation plans are discussed, agreed, and recorded.

## **Poor Mainstreaming of Discrimination, Gender, and Income Poverty**

### ***Discrimination***

In many NAPs, the Decade's cross cutting themes of discrimination, gender and income poverty are not mainstreamed. A brief discussion of major gaps follows.

The OSCE, European Commission Against Racism and Intolerance, Council of Europe, United Nations Committee for the Elimination of Racial Discrimination, European Parliament, and the European Union (via the European Commission's Annual Reports on candidate country progress toward EU accession) have all repeatedly highlighted the role that discrimination and prejudicial attitudes play in limiting Romani access to social and economic opportunities and services, including health care.<sup>67</sup> Widely shared observations that discrimination shapes Romani health suggest that plans to improve Romani health should include a wide range of initiatives to combat and redress discrimination. Instead, many of the health portions of NAPs do not specify any initiatives to fight discrimination.

Croatia, the Czech Republic, Montenegro, and Slovakia<sup>68</sup> do not mention discrimination in their health action plans. Worse, Slovakia appears to perpetuate discriminatory explanations of Romani health status in naming the first determining factor of Romani health as "native predisposition."<sup>69</sup>

Hungary will "fight against direct and non-direct discrimination," but how it will do this is not explained. Bulgaria will train an undetermined number of health providers in the ethnic and cultural specificities of Roma, but the plan does not state that these activities will be geared toward combating discrimination. Romania will "promote intercultural education among all categories of medical personnel nationwide." And while discrimination is named as a corresponding cross-cutting theme, no monitoring mechanisms or remedies to discrimination are specified. The Serbian plan most explicitly ties activities to discrimination, as the government plans to educate health personnel and Roma on patient's rights. Further, the plan states that a minority rights NGO will monitor implementation. Nonetheless, activity descriptions are brief and unclear, and indicators are too broad to be verifiable, e.g. "patients rights [will be] implemented."<sup>70</sup>

Failure to plan programs that acknowledge and address past and present discrimination as a key social determinant of Romani health will compromise the efficacy of all activities.

It will also reduce Romani community support for governmental efforts to improve Romani health. Encouraging Roma to visit the doctor will have little effect if they continue to be treated poorly by many physicians. Mediators will be less effective if physicians perceive their appropriate role as lessening doctors' work, rather than as an element of a comprehensive program to compensate for entrenched disadvantage. More broadly, community health will not improve if the prejudicial attitudes underlying inequitable resource distribution continue.

### *Gender*

Romani women's rights advocate Nicoleta Bitu evaluated the health components of Decade Action Plans to assess the extent to which gender was sufficiently mainstreamed and presented her report to the International Steering Committee of the Decade of Roma Inclusion. She noted that the following specific activities for Romani women's health are foreseen: (1) Bulgaria will address breast cancer prevention, pregnant women, and the issue of early marriages, (2) FYR of Macedonia will introduce regular annual medical exams for Romani women, (3) Romania will undertake information campaigns targeting Romani women in preventing breast and uterine cancer,<sup>71</sup> (4) Montenegro will improve Romani knowledge in the area of breast and uterine cancer, and (5) Slovakia will improve sexual health. These measures, which in the case of FYR of Macedonia and Montenegro in particular, are very vague, do not address the range of Romani women's health needs, nor do they seek to undercut the gender inequities that shape Romani women's vulnerability to poor health. In some cases, NAPs appear to reflect traditional majority population fears about Roma as purveyors of disease and producers of babies,<sup>72</sup> as opposed to a reproductive rights perspective. For example, Slovakia proposes to achieve "improved sexual health" through the provision of information relating to sexually transmitted infections (STIs) and planned parenthood. No other activities are indicated. In other action plans, Romani women's health is not mentioned *at all*. A comprehensive approach to women's health should address reproductive and maternal health, maintaining well-being and health for an entire lifetime, illnesses and vulnerabilities specific to women, and women's rights and capacity to negotiate interactions and access health care relating to all of these areas.

As elements of NAPs, RHM programs also need to incorporate an overall strategic framework for addressing women's health and power imbalances between Romani women and men. Mediators in Romania are currently all women, as the program planners thought this would empower women. However, current research within reproductive health suggests that reaching men is key, because men's power, attitudes and behaviors can hinder or advance reproductive health.<sup>73</sup> Since the female RHMs in Romania work primarily with women, their capacity to reach men is limited. When asked about having mediators of both sexes, almost all RHM clients and RHMs in Bulgaria and Romania responded that this would be a positive development.

Just as individual Romani health programs require an overall strategic framework, so to do Romani women's health programs. Initiatives addressing women's health concerns must

consider the particular impact of discrimination on Romani women and the gender dynamics within Romani communities as well as within the society at large, among other factors. RHM programs should address those with more and less decision-making power (men and women) and consider the most important taboo Romani women's health issues, such as sexual health, vulnerability to trafficking, and domestic violence.

### ***Income Poverty***

Using EU Public Health Programme funds, the European Health Management Association and EuroHealthNet developed criteria for assessing how well NAPs integrate the relationship among health, poverty, and social exclusion. Some of these criteria can be used in looking at Decade Action Plans, including *inter alia*, how well NAPs address affordability of services and remove financial obstacles, and to what extent NAPs protect against adverse effects of out-of-pocket payments.<sup>74</sup> Major cost obstacles to accessing health services were cited repeatedly by study participants, but Decade action plans do not foresee concrete solutions to the high cost of drugs, demands for out-of-pocket payments, or the cost of travel to health facilities. This notable omission suggests that the plans were developed in isolation from larger health system reform needs, and that governments are not yet willing to address some of the biggest barriers to improved Romani health.

### 3. Components of Health Effectively Addressed by Mediators in Finland, Romania, and Bulgaria

The following observations are taken primarily from the interviews, focus groups, and surveys conducted as part of the site visits. The study team found that mediators were quite effective in addressing some of the individual level obstacles to improved health, but less effective at addressing many of the social conditions underlying overall Romani marginalization and poverty.<sup>1</sup>

#### Reducing Bureaucratic and Communication Obstacles to Improved Romani Health

In Romania and Bulgaria, RHMs appear to spend much of their time: (1) facilitating communication between patient and doctor, (2) helping clients to complete bureaucratic procedures, and (3) communicating with the Romani community on behalf of the public health system.

## **Facilitating Patient/Doctor Communication**

Facilitating communication between patient and doctor is one of the most important elements of the RHM role. To more clearly identify the content of mediated doctor/patient interactions, RHMs were asked to comment on the frequency with which they encounter certain communication obstacles. With minimal variation across countries and sites, RHMs stated that the following occur frequently:<sup>2</sup>

- ▶ The client has not followed treatment in the past.
- ▶ The client incorrectly expects treatment to work in a short time.
- ▶ The client does not speak enough of the dominant local language to understand the physician or to make him/herself understood by the physician (e.g. the client speaks Romany or Turkish as a native language, or is poorly educated and is unable to use or understand basic medical terms).
- ▶ The health professional does not understand the client's behavior.<sup>3</sup>

In these situations, the linguistic interpretation or explanations of an RHM to the doctor or client about expectations and rationale for certain behaviors or medical treatments greatly improve the effectiveness of a physician visit. The patient is better able to understand steps that need to be taken for his/her own health, and the physician is better able to understand the patient's illness. The presence of the mediator is especially helpful in cases where a patient is illiterate. RHMs described drawing diagrams to illustrate for clients when pills should be taken and reading hospital discharge forms to inform patients that they must return for subsequent check ups or specialized care.

## **Navigating Bureaucratic Procedures**

RHMs also dedicate a substantial amount of their workday to assisting clients with negotiating the continuum of bureaucratic procedures necessary for an effective interaction with a physician. This may include assisting clients to obtain the documentation necessary for accessing health services and social assistance (e.g. birth certificate, identification or health insurance), and enrolling clients on GP rosters. Data from the Romanian Ministry of Health indicates that as of July 2004, Romanian RHMs had helped to register 108,632 children, assisted 40,015 people in obtaining health insurance, and helped 1,180 people get identity documents.<sup>4</sup> No such data is available in Bulgaria.

## **Communicating with the Romani Community**

RHMs perform community outreach on behalf of local GPs or the local public health office. Outreach frequently consists of visiting ill people and convincing them to visit the doctor,

encouraging pregnant women to get prenatal care, informing community members about family planning and STI prevention methods, and reminding individuals of the need to vaccinate children. The time and resources available for this important task may be sublimated to other more immediate needs, such as accompanying clients to see a physician. Romanian Ministry of Health data show that as of July 2004, 3,521 women were registered with GPs as a result of RHM support, 12,836 children were vaccinated following RHM intervention, and RHMs provided 4,259 “health education actions.”<sup>5</sup> No similar data is available for Bulgaria.

In Finland, mediators do not confine their work to the medical sector, but they do facilitate communication, assist in navigating bureaucratic procedures, and communicate with the Romani community on behalf of public authorities. Clients report that mediators have helped them to fill out forms for housing, social, pension or health assistance; identify appropriate authorities and providers of special services, such as drug abuse support; discuss a child’s educational program with a teacher or school official; and access state support for the purchase of traditional Romani dress.

While the clients interviewed for this study certainly comprise a biased sample, as they were almost all recruited to participate in the study by mediators, they almost uniformly reported satisfaction with mediator assistance in the above areas. GPs and nurses interviewed also felt that RHMs successfully addressed bureaucratic and communication obstacles to improved Romani health, and undertook important basic community outreach on behalf of the public health system.<sup>6</sup>

## Risks of Dependency and Opportunities for Multiplication of RHM Successes

### Dependency

The risk posed by mediators continuing to fill a communication gap between clients and medical providers is that both clients and physicians become dependent on the mediators. For their part, doctors may put little effort into explaining a diagnosis or treatment to a client if s/he knows that the mediator is capable of doing this. Indeed, with the exception of one site in Romania,<sup>7</sup> RHMs reported that they frequently encounter situations where physicians do not sufficiently explain a diagnosis or treatment.<sup>8</sup> Instead of encouraging doctors to adopt a health promotion approach of enhancing patient agency and health literacy, mediation may actually relieve doctors from passing on essential information in a manner that a patient understands—duties that the general population expects doctors to provide. Paradoxically then, mediation may serve to increase the distance between patient and doctor, and, unless the mediator seeks to educate the patient, may perpetuate the need for health mediators. This problem is not isolated to the doctor/patient interaction; a mediator in Finland explained that teachers and school officials often become considerably less pro-active when a mediator is present.<sup>9</sup>



The same risk of mediator dependency exists for patients. Roma who are scared of going to the doctor may prefer to have the mediator speak on their behalf.<sup>10</sup> A few mediators even described their task as “speaking for the patient.” In effect, many clients and mediators do not view the purpose of mediation as allowing two parties to effectively communicate with each other, but as a way to avoid, rather than minimize, the large power differential between physicians and Romani clients. Mediator work should include taking steps to decrease this power differential. However, in practice, none of the RHM curricula appear to address patient empowerment, although the manual given to Romanian RHMs does discuss internalized oppression, and ways in which mediators can help clients to overcome “self under-estimation,” “lack of power and will,” and “distrusting oneself.”<sup>11</sup>

Mediators speaking for a patient may enable that patient to pursue care in certain situations, but mediators should also orient their approach toward long-term goals of educating and encouraging patients, so that they become able to speak on their own behalf. A few mediators indicated that they orient their activities toward community building and empowerment. For instance, one mediator from Bucharest explained that she enters new communities without her notebook, introducing herself and encouraging community members to describe and discuss their shared community priorities. This approach, however, is not institutionalized in RHM programs. There are examples of Romani health programs that in their design and implementation focus on enhancing client capacity for communication. For instance, the Romani peer health education project implemented by Doctors of the World in Kosovo sought to teach Romani community members about the social determinants of health and to mentor them in how to present and discuss these issues with policymakers.<sup>12</sup> A Health and Social Development Foundation project in Sofia, Bulgaria, trains peers to assist fellow Romani community members to transform their health communication approach and abilities.<sup>13</sup> In Serbia, a project by the Romani women’s NGO Bibija adopts a role-playing approach to empower Romani women to negotiate sexual and social interactions with their families and communities.<sup>14</sup>

Institutionalizing a focus on health literacy would ensure that enhancing health knowledge and autonomy becomes an explicit aim of mediation, rather than “helping doctors.” Mediators could then play a bigger role in decreasing the long-term need for mediation.

### **Opportunities for the Multiplication of RHM Successes**

It would be beyond the scope of the RHM role for them to systematically address the bureaucratic and communication obstacles to improved Romani health. This is because mediation is generally understood to enhance communication within the current system of health provision, rather than to transform the system. However, policymakers can capitalize on the knowledge accumulated by RHMs to improve existing RHM programs. On the basis of this experience, policymakers could design complementary programs that would transform the current system by systematically addressing bureaucratic obstacles, poor physician communication, or poor Romani health literacy.

At the level of patient-doctor interaction, RHM knowledge could be used to re-orient health mediation programs in a way that would mitigate some of the risks mentioned earlier. For example, GPs, health ministry representatives, and RHMs could discuss ways physicians and RHMs could cooperatively increase the health literacy of Romani patients. Given their in-depth knowledge of frequent difficulties patients have in understanding or implementing physician recommendations, mediators could assist physicians in improving their communication with all socio-economically disadvantaged patients. For example, physician practice changes such as speaking without jargon and giving oral explanations for all written information may make a patient feel less intimidated and better able to ask the doctor informed questions in subsequent visits.<sup>15</sup> Instead of just compensating for poor health knowledge and confidence on the part of the patient and inadequate communication on the part of the physician, RHMs and physicians could work together to transform patient knowledge and confidence and physician communication skills.

At the level of overall health strategy, RHM input could ensure that programs addressing Roma are feasible and desired by the community. Unfortunately, RHMs and other NGO stakeholders in Romani health noted that mediators are almost never consulted by health ministries or other NGOs to assist in designing Romani health initiatives.<sup>16</sup> Mediators are provided with few opportunities to pass qualitative information up, particularly information beyond a description of their daily activities. There do not appear to be any mechanisms, for example in Romania, to have mediators substantively contribute to discussions among the Ministry of Health, the Ethnic Minorities Health Problems Foundation, and Romani CRISS about current RHM programs and overall Romani health priorities. Possible mechanisms for contribution include cooperative brainstorming and policy planning sessions involving RHMs and professionals who address or represent other marginalized groups. If incorporated into government policies, this input would maximize health reform feasibility, validity, and appropriateness. Moreover, consultation with RHMs about their perceptions of program and health reform needs would add to RHM job satisfaction.

In short, existing RHM programs can be altered to increase mediator input, likely leading to stronger mediation programs and to the development of other needed health programs. Nonetheless, given the nature of their role, mediators are unable to address many systemic limitations to improved Romani health.



## 4. What Current RHM Programs Do Not Address

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, poor 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.

### Discrimination

Cases of prejudicial treatment and human rights violations against Roma throughout Central and Eastern Europe highlight the prevalence of discrimination in the medical system. Over the past five years, human rights groups have documented cases of forced or coerced sterilization, segregated maternity wards, verbal abuse, negligent treatment, hospital or physician refusal to treat, ethnically based insults, denial of access to medical records, and refusal to provide medical benefits.<sup>1</sup> Physicians may also actively thwart Romani patient efforts to claim their rights. For example, following allegations of forced sterilization in Slovakia, hospital staff in the town

of Krompachy verbally abused pregnant Romani women and accused them of ingratitude for their good health care.<sup>2</sup>

RHM programs have been found to decrease prejudice among physicians who participate. About half of interviewed mediator clients in Bulgaria, Finland, and Romania noted that they are less likely to be treated in a discriminatory manner by a physician, medical staff person, or service provider if a mediator is present.<sup>3</sup> Some explained that they had been refused enrollment on a GP roster, but that when they went to enroll with a mediator, they were allowed to do so.<sup>4</sup> Several clients indicated that ambulances often come after two hours or not at all, but that they were much more likely to come if an RHM called. The Advisor on Romani health within the Romanian Ministry of Health and Family noted that anti-Romani sentiments among health professionals visibly decreased after a year of program implementation.<sup>5</sup>

The improvements described above are real successes that may eventually lead to sustained changes in practices among the medical community, and thus to decreased discriminatory behaviors even in cases where mediators are not involved. However, mediators will never be able to eradicate discrimination in the health profession. Because intercultural mediation has developed primarily as a way to address immigrant populations in Western Europe, the model does not attempt to redress hundreds of years of entrenched discrimination.<sup>6</sup> RHMs often do not have the moral or political authority to influence the actions of individual physicians. Indeed, RHMs noted that they sometimes witnessed discriminatory treatment even when they themselves were present.

Additionally, the long length of time required for changing discriminatory behavior makes it unlikely that RHM programs can adequately reform the behavior of many physicians in a short period. Mediator clients confirmed that discriminatory treatment often resurfaces when an RHM was not present—doctors refuse to provide care,<sup>7</sup> reveal preconceptions tainted by “racial hatred,”<sup>8</sup> request payment for documents that should legally be free,<sup>9</sup> and shout at Romani patients.<sup>10</sup>

Given the nature and scope of their role, mediators are also limited in their capacity to address discrimination at a community level. Poor complaint mechanisms and the inability to contribute to the overall policy environment do not allow mediators to challenge the impunity that discriminatory physicians sometimes appear to enjoy. The ultimate responsibility for ending discrimination falls on health providers and the government, through strong policies and programs that address the legacy of long-term exclusion and prevent or remedy ongoing discrimination.

Unfortunately, NGO observers in Bulgaria and Romania noted that thus far, governments have, for the most, part failed to follow through on their plans to systematically address racial or social discrimination.<sup>11</sup> In its most recent report about Bulgaria, the European Commission against Racism and Intolerance confirms this view.<sup>12</sup> The latest European Commission report on Romania’s progress toward EU accession draws similar conclusions.<sup>13</sup> Needed systemic measures include strengthening patients’ rights and antidiscrimination legislation

and complaint mechanisms, publicizing the existence and negative effects of discrimination among the medical community and the population at large, training physicians in the cultural specificities of minority groups, and raising awareness among the overall population about patients' rights.

Finally, in addition to mechanisms and programs, the government should publicly acknowledge the prevalence and harmful effects of past and present discrimination. The negative impact of past discrimination on current governmental programs has been documented in other settings. Studies of the African-American community in the United States reveal that African-American trust and engagement in the health care system is reduced by memories of past discrimination and human rights violations. African-Americans are less likely to participate in current governmental programs and studies aiming to lessen inequalities because of this distrust.<sup>14</sup> Therefore, governments should disclose information relating to past discriminatory policies and openly acknowledge the validity of Romani community anger and fear concurrent to the implementation of Romani health programs.

## Income Poverty

Obtaining health care in Bulgaria and Romania requires individuals to make monthly payments for their health insurance, as well as pay for drugs, transportation to health care facilities, and official and unofficial out-of-pocket payments (bribes) to health providers. RHMs cannot remove these barriers to care.

RHMs, clients, and providers in Bulgaria and Romania generally agree that clients' lack of money to pay for treatment is the most common obstacle to accessing health care.

County public health authorities in Romania cited insufficient financial resources as the second most important cause of public health problems among the Roma.<sup>15</sup> In response to these realities, Bulgarian physicians stated that they often prescribe less effective, but less expensive medication to Romani clients.<sup>16</sup>

Bulgarians and Romanians who qualify for social assistance (based on their income) are eligible for free health insurance, and everyone under 18 is entitled to free health care in both countries.<sup>17</sup> RHMs publicize these rules, and work to obtain free health insurance for those who are eligible. However, many poor Bulgarians and Romanians do not qualify for free health insurance, and are still unable to pay the fees. Among the Roma, the number of uninsured is extremely high; 46 percent of Bulgarian and 37 percent of Romanian Romani respondents to a UNDP survey claimed to be uninsured.<sup>18</sup>

Out of pocket payments are almost universally expected by physicians, and considered by them to be a legitimate part of their salary. However, these illegal payments have been found to disproportionately affect access to care for the poor, who spend a much a higher percentage of their income on out-of-pocket health care costs.<sup>19</sup> And corruption within public institutions

has been found to increase alienation and disengagement from public life, making the poor feel more voiceless and marginalized.<sup>20</sup>

A World Bank survey found that the Romanian health service is perceived to be the most corrupt institution in the country.<sup>21</sup> Households reported that the likelihood was 66 percent that they would make an unofficial payment for a hospital stay, and 32 percent that they would make an unofficial payment to see a general practitioner.<sup>22</sup> A study in Bulgaria found that annual “unregulated payments” to the Bulgarian health care system totaled €800 million, an amount almost equal to the health budget.<sup>23</sup> While it is not known if Roma are asked to make these payments more frequently than majority ethnicity clients, about half of those interviewed or participating in roundtables noted that they felt they had to make payments in order to see a physician. Studies in other settings have found that the expectation that out-of-pocket payments are necessary deters people from seeking health assistance and, once advice has been sought, from pursuing the most appropriate treatment.<sup>24</sup>

Inability to pay is not a “Romani problem,” it is a shortcoming of the health care system and should be addressed as such. But, while income poverty limits health care access for much of Eastern Europe’s poor, Roma are disproportionately represented among this group. Addressing the prohibitive costs associated with health care should therefore be a main component of Romani health strategies, alongside overall health reform.

## Doubly Marginalized Groups

In its current manifestations, Romani health mediation does not adequately address the need of doubly marginalized groups, such as Romani women, Romani persons with mental or physical disabilities, Romani drug users, and Romani sexual minorities. Some Romanian RHMs have expressed an interest in learning how to address domestic violence, a major unaddressed health concern for Romani women. This was met by widespread resistance on the part of program implementers, because it is perceived as a taboo subject within the Romani community. Ironically, it is in part its taboo status that makes domestic violence such a negative influence on Romani women’s health and overall community health.

Other doubly marginalized groups receive little if any attention. With the exception of women, training curricula in the three countries studied evidently did not mention any doubly marginalized groups or ways in which the intersection of identities shape vulnerability to poor health. When asked about their experiences in dealing with individuals with special needs, mediators in Bulgaria, Finland, and Romania almost universally stated that they had never worked with such persons. Several indicated that they had helped families to obtain social assistance in cases where a member has severe disabilities and is unable to work, but none knew of ways to support these families beyond enrolling in social assistance. Other programs, however, have entailed the discussion of such difficult topics in Romani settlements. Many

Romani women's organizations address domestic violence, and the Doctors of the World peer health education program trained educators to discuss domestic violence, trafficking, and gender roles.<sup>25</sup> Comprehensive efforts to decrease health inequalities between ethnic minority and majority populations should also consider inequities within minority populations. Mediators could better serve the most vulnerable if they had the training and referral resources to address doubly marginalized groups.

## Health Policy and Legislation

Because of lack of resources, capacity, recognition or political influence, RHMs are limited in their capacity to push local authorities and providers to honor existing health insurance and administrative laws or to improve existing laws.

The following examples illustrate how RHMs must work within legislative structures that limit access to health care for the poorest members of society or that compromise RHM work by providing insufficient remedies, and how RHMs are often unable to compel compliance with existing laws.

### **Bulgaria**

A recently passed amendment to Bulgaria's health insurance law resulted in one million Bulgarians losing their health insurance coverage<sup>26</sup> (13 percent of the overall population)<sup>27</sup> because they were delinquent in paying into the system. The least expensive way for them to regain insurance is to pay a fine equal to three months of fees. This fine is not subtracted from the total owed, and payment will reactivate insurance for only one year, provided that the person is not delinquent again during that year. Following that year, people must pay all delinquent fees at a high interest rate.<sup>28</sup> The passage of such laws seems to stem in part from a lack of understanding of the need for legislation that compensates or lessens disadvantage. When asked about the need for legislative changes, representatives of the Bulgarian Ministry of Health indicated that all Bulgarians have the possibility to access health care under Bulgarian law, so no legislative changes are required.<sup>29</sup> Given the entrenched disadvantage many in the Romani community face, equality is not likely to be achieved simply by treating everyone the same.<sup>30</sup> But, Bulgarian RHMs can only inform community members about the fact that they can regain insurance through payment of a fine. They have a low professional status and do not have opportunities to transmit qualitative information to the Ministry of Health about the extent of Romani disadvantage or to participate in policy formulation on this issue.<sup>31</sup>

### **Romania**

Administrative laws may encourage people to make choices that have a negative impact on their health, and RHMs are limited in their capacity to guide these choices or to change the



law. They may only be able to mitigate the negative impact of a particular decision. In Romania, birth registration documents are necessary to access social assistance for an infant. According to the law, a mother must travel to the hospital where she gave birth to obtain the documents, which cannot be rendered at the time of the birth. However, if a woman gives birth at home, the local mayor will register the birth, and no travel costs will be required. Since they do not have sufficient funds to pay the transport costs of a trip to a far off hospital, some of the poorest women living in isolated rural areas give birth at home.<sup>32</sup> The law has clear unintended negative consequences for women's and children's health. Unless a mediator is able to negotiate an irregular transaction, such as securing registration by the mayor despite the fact that the infant was born in a hospital, mediation cannot address the inadvertent administrative incentives to at-home birth.

Another example from Romania involves recently passed antidiscrimination legislation meant to harmonize national law with EU antidiscrimination requirements that actually places the burden of proof on the person making the complaint.<sup>33</sup> This is contrary to Article 8 of the EU Race Directive, which requires that the respondent in civil cases prove that there has been no contravention of equal treatment.<sup>34</sup> The negative results of rights claiming cited earlier demonstrate the unequal power balance between physicians and patients and the justifiable fear that bringing a complaint may result in receiving inferior health care or being subject to abuse. This inadequate antidiscrimination legislation cannot be remedied by RHM activities. Moreover, it compromises the effectiveness of RHMs, as mediators will not refer clients to mechanisms that may result in negative outcomes for the client.

Other cases in Romania suggest that the laws may be adequate, but they are not followed. RHMs reported their frustration at being able to address some of the social determinants of health on an individual level, but not being able to compel others, such as utility providers or local officials, to comply with existing laws. For example, a mediator in Bucharest explained that the water was turned off twice during the previous month in a community in which she works. The negative health impacts of lack of potable water (particularly in an urban setting) are clear. The stated reason was nonpayment of bills, although many residents had paid their bills. In her capacity as local health mediator, she went to the water company to request that the water be turned back on for hygienic reasons, and stated that there is no legal justification for cutting off the water of those who had paid their bills. She was unsuccessful, so she went to inform local authorities about the water company's breach of the law. Despite her efforts, the water was not turned back on.<sup>35</sup>

As demonstrated, mediators cannot fix deficient legislation; they can only assist clients in understanding and navigating the system. Creating routines whereby mediators regularly share qualitative information with policymakers may help to identify weaknesses in laws and regulations, but persons with legislative power are ultimately responsible for making changes.

## Lack of Resource Commitment and Political Will at the Local and National Levels

Evidence of major gaps in political and financial commitment to RHM programs include: (1) the insufficient number of mediators with too few resources in communities that are served, (2) high numbers of municipalities and physicians that do not participate, either because of lack of funds or of local interest, or, (3) the number of mediators who are selected based on favoritism rather than capability. These weaknesses in implementation result from program design decisions, and thus cannot be remedied by mediators. At the same time, they compromise mediator effectiveness. Depending on whether political will is weaker on the national or local level, advocates and policymakers may want to consider various ways of strengthening the oversight role and financial input of national or municipal authorities.

### **Insufficient Number of Mediators with Too Few Resources**

The two RHMs in Stara Zagora, Bulgaria, cooperate with two GPs, and cover a catchment area of 26,000 residents. These residents live in three different neighborhoods.<sup>36</sup> Some RHMs have fewer clients; two working in Bucharest are collectively responsible for 1,700 community members, and another colleague in Bucharest is singly responsible for 3,000.<sup>37</sup> However, this still exceeds the 500–750 per RHM stipulated in the Ministry of Health's ordinance establishing the mediator program.<sup>38</sup> Indeed, mediators in the Bulgarian and Romanian roundtables mentioned the overwhelming need for their services. They explained that they were unable to devote sufficient time to each client and to pro-actively identify new clients and needs in the community. Bulgarian, Finnish, and Romanian mediators complained that they lacked logistical and financial support for the administrative tasks entailed in their work.

Some Finnish mediators, for example, explained that they are responsible for serving a wide geographic area, and must cover their own travel expenses. Romanian RHMs receive a monthly bus pass for their necessary travel, but the mediators in Bucharest explained that the bus is much slower than the metro, which they cannot afford. Two mediators in Bucharest are required to travel by bus one hour each way to register daily that they are working.<sup>39</sup> Local health facilities (usually hospitals) in Romania should reimburse RHMs for a portion of their administrative costs. But, some mediators noted that this never happens, and others explained that they are asked to sign receipts for higher amounts than they actually receive.<sup>40</sup>

Bulgarian RHMs are required to use their own phones and are not reimbursed for calls made when conducting RHM business.<sup>41</sup> Romanian RHMs receive three phone cards per month, but phone cards only work in payphones, making the RHMs unreachable by phone. Many have purchased a mobile phone and cover these costs themselves.<sup>42</sup> While the number of clients desiring assistance is overwhelming, the program structures inadvertently provide disincentives to serving more clients. Since scheduling meetings or accompanying patients to

the doctor requires costly phone calls or travel that must be paid from the mediators' pocket, mediators may try to minimize these expenditures.

### **Lack of Political Will at the Local Level**

Lack of local level commitment to improving Romani health is often demonstrated by municipalities and physicians refusing to participate in RHM programs. Municipalities may explain this failure as being due to resource constraints. In Timiș County, Romania, three RHMs were trained, but none of them were hired. The local Directorate of Public Health claimed that it lacked the resources to hire a mediator.<sup>43</sup> Since the salary costs would be borne by a national body, the only financial inputs required at the local level would be the time of those supervising the mediator. The resource constraint argument has little credibility in this instance, since the resources required at the local level are not substantial and the need is great. Officials from several Romanian municipalities replied to the initial Ministry of Health inquiry regarding need for mediators by stating that discrimination and poor communication between Romani patients and physicians are not problems in their regions.<sup>44</sup> Given the evidence to the contrary, it is likely that these municipal officials do not prioritize Romani health problems and/or attribute inferior Romani health status to the Roma themselves.

Lack of local interest is also a problem in Bulgaria. Fifteen municipalities were included in the initial PHARE project, and, in each, RHMs and GPs were trained and local health facilities were provided with medical equipment. Despite this, several of these municipalities have stopped supporting health mediation activities.<sup>45</sup> Participating in the initial program necessitated agreeing to maintain RHM program activities, and the donation of medical equipment should compensate for the financial outlays associated with maintaining mediator programs. Again, municipal decisions to not allocate funds to Romani programs are most likely not due to financial imperatives. Stara Zagora, the municipality with 2 RHMs for 26,000 residents, is one of the wealthiest municipalities in Bulgaria. Failure to support these mediators with public funds is due to the perceived political insignificance of Roma.<sup>46</sup>

Even in municipalities that are covered by RHM programs, individual physicians may refuse to participate.<sup>47</sup> About 20 percent of Romanian physicians<sup>48</sup> refuse to work with RHMs, claiming, among other things, that they have a high level of education and do not wish to work with inadequately trained colleagues. Since one of the mediators' primary tasks is to facilitate a patient's progression through the medial system, they are limited in their capacity to do their work if there are not enough doctors willing to work with mediators and to accept Romani patients.

So few physicians in Kyustendil, Bulgaria, are willing to work with RHMs that the Ethnic Minorities Health Problems Foundation provides volunteer doctors from Sofia to work with mediators and their clients. These volunteers certainly provide a valuable service to the community, but they are not a sustainable part of the system. The effectiveness and scope of RHM work in Kyustendil is thus partially dependent on unsustainable physician coverage. In Kosovo,

peer health educators were hardly able to secure any physician cooperation. They indicated that they had attempted to forge relationships with local Ministry of Health officials and doctors, but they were repeatedly rebuffed. Mediation requires good will on the part of both parties; mediators do not have much power to convince parties to participate.

### **Lack of Political Will at the National Level**

Of the three countries closely studied, the selection of unreliable nongovernmental partners seems to be a problem only in Romania, as the smaller-scale programs in Bulgaria and Finland are closely monitored by local NGOs or municipalities. As indicated, the Romanian government cooperates extensively with the Roma Social Democrat Party in selecting RHMs. Both the European Commission and the Open Society Institute have decried the Romanian government's reliance on the party, as it prevents meaningful civil society participation.<sup>49</sup> The party often does not represent the needs or the desires of the community, but reflects the inequitable distribution of power within the community. For instance, depending on the competence of the party branch, RHMs may be selected based on their qualifications, or, they may be selected as a part of an informal system of political patronage. It is not clear how many RHMs in Romania fail to do their job, but one close observer estimated that the number may be as high as 25 percent.<sup>50</sup>

Other cases involve active party opposition to mediation. In Bacau, Romania, the branch of the Roma Social Democrat Party did not want RHMs, most likely because they perceived a mediator as a potential threat to their power in the community. They threatened anyone who came forward as an RHM candidate. It was only the concerted intervention of an international NGO that ensured that mediators were finally trained and hired.<sup>51</sup>

## **Remedies for Lack of Political Will**

In the face of decentralization and financial constraints, central governments (and thus ministries of health) in Eastern Europe are inclined to maintain control over resources, but to task local governments with as many expenses as possible.<sup>52</sup> As a result, while ministries of health may play a role in designing RHM programs, they are likely to seek external funding to support them, or push municipalities or GPs to pay. There are two major draw-backs to local level financial support. The first is compromised neutrality; if RHMs are accountable to local level authorities, this may result in tensions or conflicts of interest at the local level. Secondly, if municipalities are entirely responsible for implementation and national supervision is weak and local level political will is poor, the likelihood of failure to follow through increases. On the other hand, progressive municipalities may have the motivation and resources to create RHM programs that may not yet be feasible on the national level. For example, there is not yet a national program in Serbia. In 2003, the Romani NGO, YUROM Center–Niš, and the

municipality in Niš, Serbia, received external funding to create an RHM program. After a year of pilot implementation, two RHMs are now employed by the municipality.<sup>53</sup> This model was used in designing the national program envisaged in the Decade Action Plan.

Regardless of whether mediation begins on the local or national level, policymakers should ensure the commitment of adequate resources and incorporate strong supervisory mechanisms that facilitate local level implementation. Poor local-level follow through plagues many elements of reform in Eastern Europe, particularly those elements that do not enjoy widespread local support. Given the fact that most politicians do not feel accountable to the Romani community,<sup>54</sup> they do not prioritize financial or human resource support for programs addressing Roma. Discussions of how to remedy this disconnect is beyond the breadth of this study. However, a few solutions may include making national disbursement of other funds contingent on local level implementation of Romani health mediation, facilitating fora for municipalities to share positive examples with one another, creating funding mechanisms that tie support for RHM programs with other initiatives that may be more desired by municipalities, publicizing the positive outcomes of RHM programs at the national level, having municipalities and national level entities share the costs of mediation, and creating more rigorous program implementation monitoring mechanisms at the national level. National governments should also create strong accountability mechanisms for nongovernmental partners. Governments may perceive partnership with a national organization such as the Roma Social Democrat Party as more efficient because the network of local offices provides a ready made framework for Romani participation and RHM recruitment. However, relying on such a partner could ultimately lead to program failures, and thus be inefficient in some regions.

International donors can ensure local level implementation of programs they fund by conducting comprehensive evaluations that examine not just national, but also local level implementation, as well as by funding local level entities directly. Support for health reform should target physicians in particular by including clear directives and training relating to patients' rights and nondiscrimination.

## 5. Conclusions and Recommendations

Policymakers concerned with Romani health should broaden their conceptions of the causes and appropriate remedies for inequalities between Roma and overall population health. These broadened conceptions should be reflected in: (a) RHM programs; (b) NAPs for Romani health; and, (c) national strategies for health reform, social inclusion, minority rights, and women's and youth empowerment. The following recommendations thus target three major actors involved in governmental efforts to address vulnerable groups—RHM program implementers, national level policymakers, and donors. The recommendations suggest ways in which RHM program implementers can re-orient RHM programs; national policymakers can strengthen and integrate NAPs for Romani health and broader national strategies; and donors can better support these governmental programs as well as nongovernmental efforts to influence governmental policy or to pilot innovative models of health promotion in the Romani community.

### Recommendations to RHM Program Implementers

Current programs should be altered to ensure that mediators are enhancing communication, as opposed to assuming duties that should be the doctors' responsibility. Moreover, the RHM health promotion role should be deepened, making RHMs an integral part of the public health

system. RHMs should work with doctors to increase patient health literacy and conduct community-based health education activities.

1. ***Evaluate ongoing programs with the need for program refocus in mind.*** Since both Bulgaria and Romania are actively expanding their programs, current program structure should be evaluated by RHMs, clients, social workers, municipal and national authorities, and physicians. Focus groups could develop short, medium and long-term goals for RHM program implementation and overall Romani health strategy. These evaluations should be undertaken regularly and complemented by new systems that institutionalize RHM information and priority sharing with policymakers. They should assess stakeholder satisfaction with current program structure, as well as their thoughts about how programs could be refocused to better address the social determinants of health.
2. ***Re-orient RHM training and role definition to facilitate patient empowerment through health literacy development.*** RHM trainings should include concrete ways for mediators to cooperate with doctors to enhance patient health autonomy, and RHMs should be prepared to ask physicians to provide complete explanations rather than expecting mediators to do this. Physicians may initially be reluctant to adopt this approach. Program planners could employ several counter arguments: (a) ensuring that the physician provides health information to patients reinforces the role of the doctor, and not the RHM, as health expert (b) patients with higher levels of health literacy will have more realistic expectations of physicians and the health system, and (c) improved health literacy will result in long-term health gains, improved use of preventive services, and decreased use of emergency services. RHM training should also address the risk of client dependency, and explain that the RHM role must not be to meet client expectations of state paternalism, but should be to help clients to pro-actively seek and use health information, prevention services, and treatment services. RHM trainings already involve role-playing; this technique could be used to teach RHMs how to transform client approaches to health. Other innovative techniques, such as community health action events and theatre and games focused on sensitive health topics could also be used more frequently.
3. ***Provide training and support to address some of the special needs of doubly marginalized groups.*** Deepening the health promotion orientation of Romani health mediation should include discussion of especially vulnerable populations within the Romani community, and ways in which identities intersect to shape vulnerability to ill health. Among other issues identified by RHMs themselves, RHMs should be trained in the social or human rights approach to physical and mental disability, the importance of gender roles and domestic violence, vulnerability to trafficking or living on the street, and the particular mental and physical health needs of sexual minorities. Just as physicians should be

trained and willing to accommodate and address the needs of all patients, so too should RHMs. Understanding the health implications of extreme marginalization will inform and strengthen RHM work with families, understanding of subjugation, and information-sharing with health policy planners. Organizations representing other marginalized groups could be approached to assist in RHM training or in the conduct of community health mobilization activities.

4. ***Provide additional professional support to RHMs.*** RHMs repeatedly expressed a desire for greater professional support. This would increase their effectiveness as well as their job satisfaction. Possibilities include (a) the provision of continuing education, (b) the creation of an RHM professional association, (c) stronger supervision, and (d) increasing the professional validity of mediation.

- ▶ *Continuing Education:* Professional development efforts for RHMs should include refresher trainings in communication skills, as well as additional topics in which RHMs express an interest, such as particular health concerns and domestic violence. Established intercultural mediation programs in Western Europe provide continuing education as a matter of course, recognizing that it increases the professional capacity as well as the morale of mediators.
- ▶ *Professional Associations:* Health and social service professionals who cooperate with mediators, such as nurses and social workers, have professional associations. An RHM professional association, could, for example, have annual national meetings and more regular local meetings, with one to two full-time staff whose role entails identifying training needs and networking opportunities. Such a group would enhance RHM professional capacity and job satisfaction, provide opportunities for RHMs to support one another and jointly solve problems, and facilitate information sharing nationally and internationally. The group could also join related professional associations and governmental organizations as an observer or participant. Care should be taken to ensure that such an association is not co-opted by powerful groups, such as political parties.
- ▶ *Supervision:* Focusing supervisory meetings on substantive support, rather than activity reporting (as is the case in Romania), would make supervision more effective for RHMs.
- ▶ *Validity:* Increasing professional validity could include the provision of professional accoutrements or small incentives to mediators. Many mediators expressed their desire for an ID identifying them as RHMs. Other incentives should relate to



the RHM role, and could be distributed following a particular number of months or years in the profession. Such incentives could be shoes, bags, or other items identified by mediators themselves.

5. ***Institutionalize mechanisms to capitalize on RHM knowledge.*** RHM knowledge should be leveraged to improve RHM programs, Romani health action plans, and overall governmental efforts to promote inclusion. Institutionalization could include: creating regular forums for RHMs to provide qualitative information to supervisors, having RHMs participate in Romani health strategy development discussions, and creating links between an RHM professional association and other national and international associations. Elected representatives of an RHM professional association could meet with representatives of social work, nursing, medical, and other professional associations; as well as with international donors or organizations. National governments should consider RHMs to be an integral component of the public health system, rather than isolated staff people who help Roma. Adapting the former approach would increase the role of RHMs in designing policies to address all vulnerable groups, as well as their input into Romani strategy in other sectors.
6. ***Strengthen mechanisms of supervision and accountability.*** Local supervision should be improved; and all programs should envision a mix of accountability at the health facility, municipal, and national levels that prevents abuse of mediators or of the mediator role. Improving local supervision would mean providing regular substantive feedback to mediators, having and implementing clear punishments for failure to carry out RHM tasks, and not allowing Romani political parties or other actors to nominate mediators who are given the job as a favor. Bulgaria should not create a program whereby GPs pay mediators. The risks of such a program outweigh the potential benefits as some RHMs may perceive their goals in terms of maximum patient recruitment, rather than health promotion.
7. ***Increase physician involvement.*** Physician training and involvement should be increased in both Bulgaria and Romania, despite the fact that Bulgarian GPs have already received some training in cooperation with RHMs. This increase should be viewed as professional advancement for the doctors. Training the physicians will make them more initially accepting of mediators, and, if they are trained in patient health empowerment, they will be more effective at addressing Romani health needs. Obstacles to convincing doctors that patient health literacy is important could perhaps best be addressed by entities that have the respect of physicians and could explain the benefits to the medical community. Involvement of international agencies such as WHO or UNICEF in this kind of training might achieve this objective. Creating opportunities for international

sharing of program successes that involve physicians might also increase physician commitment and provide incentives to doctors who are less willing to participate.

8. ***Provide additional administrative support to RHMs.*** Given the low salary and high work load of mediation, RHMs should have the administrative resources necessary for their work. This could include lump sums for cell phone usage, metro passes, and bus tickets to tertiary care sites.<sup>1</sup>
9. ***Publicize the program among the overall population.*** Politicians and decision-makers should raise overall population awareness about the determinants of Romani health, and the need for programs addressing entrenched disadvantage of Roma. Publicity could consist of interviews with print and television outlets. This has already occurred in all three countries, but should occur on an ongoing basis, with mediators speaking for the program as much as possible. Publicity could also spur policy discussion about ways how RHMs could be used in the future to train other professionals or mediators who may work with incoming immigrants.
10. ***Increase the number of mediators within RHM programs that empower patients.*** Implementing the recommendations elaborated above will increase the effectiveness of current mediators. Nonetheless, the mediator to client ratio is too low in all countries, and additional mediators should be trained in patient health empowerment. While Decade countries are all constrained financially, the cost of mediation programs is fairly low. For example, the budget for the Romanian program, which is by far the largest, was approximately \$338,000 in 2004.<sup>2</sup> Allocating additional funding in conjunction with the above-described changes would strengthen overall Romani health strategies.

## Romani Health Strategy and NAP Recommendations for National Policymakers

The following recommendations broadly outline ways in which national strategies should be developed or implemented to comprehensively address Romani and overall population health, though in-depth recommendations beyond RHM are beyond the scope of this study.

1. ***Improve current health action plans to address the social determinants from a health promotion perspective.*** Decade action plans should be expanded to truly mainstream gender, income poverty, and discrimination; to include analyses of legislation related to insurance, documentation, and health and social care system structure; and to focus on

increasing service providers' awareness of socio-economic inequities or discrimination. Activities must address biases and weaknesses within both the Romani community and the medical community. For example, health education in Romani settlements should be complemented by physician training in cultural concerns, patient-centered communication, and the links between poverty and poor health.

2. ***Define benchmarks for action plan implementation.*** Decade planners should profit from the lessons learned about the poor accountability and specificity in EU-accession related human rights action plans. Apart from what is detailed above, action plans should be refined to include time frames for assessments, hiring, and evaluation. Responsible agencies, individuals, and sources of funds should be identified as well. The Decade Steering Committee could provide momentum for this by specifying some common benchmarks and indicators.
3. ***Implement all action plan components.*** Mediators lack the supporting legislation, resources, and cooperation necessary for the most effective fulfillment of their role. Failing to design or implement other elements of Romani health strategies undermines the effectiveness of Romani health mediation. And, mediation cannot be provided in isolation from the creation of patient's rights and discrimination mechanisms, legislative changes, programs to increase respect for patient's rights in the medical community, and comprehensive analyses of health determinants.
4. ***Create separate programs to address the issue of documentation.*** Reforming policies for obtaining identification and other documentation necessary to access the health and social assistance system should be a key component of any legislative overhaul relating to Romani health. However, given the amount of time RHMs dedicate to this issue and the key role it plays in limiting access to services, it warrants separate consideration here. Governments should undertake systematic efforts to ensure that both newborns and Romani adults have documentation, and that costs associated with obtaining documentation are minimized. These efforts should be pro-active; rather than waiting for individuals to come forward and request assistance, government representatives should conduct outreach in Romani settlements.
5. ***Create multiple links between the Romani community and service providers.*** Finland's continuum of mediation services is a replicable model of a comprehensive approach to Romani disadvantage. Finland has created several types of mediation between the Romani community and state authorities, including having mediators provide lectures to different service providers; creating manuals for state agencies; and having a continuum of voluntary, semi-professional, and professional mediators. Policymakers in Eastern Europe should consider which of these fairly low cost initiatives might be appropriate to their

countries. Current RHMs could play a role in developing these tools, which could also be used in the trainings and information sharing forums recommended above.

6. ***Integrate Romani health needs into overall health and social services reform.*** As indicated, Roma disproportionately suffer from health system weaknesses. This acknowledgement is key to exploring the links between Romani health status and institutionalized discrimination. However, at the same time, these weaknesses must be examined and remedied as gaps in the health system's capacity to address marginalized groups, not as "Romani problems." For example, health facilities should have ways of accommodating illiterate patients, plans for lessening and eventually eradicating out-of-pocket payments, and plans for increasing promotion activities and for addressing some commonly encountered needs of a wide range of marginalized groups.

Ministries of Health and Social Affairs should identify health inequalities within their populations, and address the structural issues and health care system weaknesses that shape and perpetuate these inequalities. In fact, the EU Public Health Programme has prioritized this approach in funding a multiyear, multicountry effort to identify and address local and national health inequalities.<sup>3</sup> Some governments, such as the Welsh government, have also created funding streams specific to inequalities in health.<sup>4</sup> This approach addresses the factors shaping vulnerability to poor health, rather than perpetuating stigma by addressing particular ethnic groups as such.

## Recommendations to Donors

Donors should support any of the above recommended activities as well as the following:

1. ***Support Decade action plan implementation monitoring or evaluation.*** Regardless of whether or not governments create benchmarks for activity implementation, civil society groups can still identify their own benchmarks and monitor implementation. To increase the political potency of their monitoring, NGOs can use EU or Council of Europe standards for health promotion and/or human rights (as enshrined in the EU Public Health Programme or European human rights treaties) to guide their evaluations. Moreover, they can also examine existing national and local level Romani health assessments and evaluate the extent to which the current Decade action plan responds to the needs highlighted by these assessments.
2. ***Build Romani and other NGO capacity in health promotion.*** As indicated, few Romani NGOs or individuals have strong capacity in health promotion, in part because the entire paradigm is new to Eastern Europe. To build organizational capacity, foundations and bi-

lateral donors could focus particularly on smaller NGOs that are not regularly EU grant recipients. In addition to supporting project implementation, donors could provide technical support in program development, particularly to programs that involve municipalities. Project partnerships between NGO and municipality partners are a major modality of EU donor support and would make small NGOs better able to access EU funds.

3. ***Enhance individual capacity for health promotion.*** Apart from supporting organizations, donors could create programs to build individual capacity. Pakiv, a foundation based in the Czech Republic, currently provides in-depth training and mentoring to Romani activists in community building. Activists are trained as a group, and then mentored to design and implement programs in their own communities. This model could be adapted specifically to the health context, and could include training in health, community health mobilization, and advocacy, as well as subsequent technical and financial support in program development and implementation.
4. ***Fund legislative or policy audits of health and social assistance laws, and associated advocacy efforts.*** Improving the legislative environment would allow RHMs to spend time currently used for addressing documentation and other issues to reach more clients and to facilitate more community health mobilization. Donors should support a concerted process of legislative advocacy that entails analysis, developing and proposing alternative laws and policy, coalition building, and lobbying.
5. ***Fund unique partnerships for legislative and policy audits that examine laws not traditionally considered in Romani health programming.*** Apart from health insurance and citizenship laws, a whole host of other laws and policies influence Romani health, including, for example, environmental and property laws, patient's rights, initiatives to reduce domestic violence, and the level of public health staff salaries. In part to prevent the ghettoization of Romani concerns, Romani organizations should be supported to develop partnerships with agencies in order to examine and advocate around how policy in many sectors affects Roma and other poor and marginalized populations.
6. ***Fund innovative health promotion partnerships to study and address double marginalization.*** New partnerships would result in improved understanding of the social determinants of health and facilitate information sharing and synergies among organizations addressing excluded populations. Donors could fund health promotion partnerships between Romani organizations and organizations representing other salient groups, such as youth, women, persons with disabilities, drug users, and so on. Projects could discern or address the particular health needs of doubly marginalized groups, and partner agencies could pool their advocacy and social mobilization resources and expertise.

7. ***Facilitate information sharing across municipalities.*** In some countries, progressive municipalities may be better able to initiate and implement RHM programs than national governments. Donors could create incentives for the replication of successful municipal initiatives by designating particular sites as centers of excellence, or by supporting information sharing. All Eastern European countries have some type of conference on towns and municipalities whereby municipal representatives meet and share experiences and present a united voice to national entities. These conferences could be used for sharing information about how to create and build political support for RHM programs and Romani programs overall. In fact, several governmental representatives asked the study team questions about successful experiences in other countries, suggesting that dedicated governmental employees want to learn about and leverage other models. The EU also has a transnational entity of municipalities—the European Public Social Platform. National and international forums could be used to discuss mediation in general and possible models of municipal support.
  
8. ***Facilitate information sharing of RHM models.*** An international governmental or nongovernmental organization could house a small center for coordination on Romani health mediation. Such a center need not entail a substantial investment, but could be a focal point for holding and disseminating pertinent information, including evaluations and critiques of RHM programs. The center could hold trainings for mediators and program planners, and could function as a library. In order to be as accessible as possible, many of the resources could be available online, and listservs and intranet could be used to share information. The library should include not only resources relating to Romani health mediation and inter-cultural mediation, but also studies of community health workers, and other health programs that include lay people as staff. This center could create links with the WHO Working Group on Social Determinants of Health and the EU Public Health Programme.
  
9. ***Fund innovative community level programming and document successes.*** Supporting innovative community level programming would spur policymaker and NGO creativity regarding ways of undertaking mediation and other kinds of Romani health programming. These programs could be implemented by local governments or NGOs, and priorities could be identified through community meetings or other participatory appraisal techniques. The Dutch foundation Spolu already uses such a community-driven model for income generation in Romani communities; this model could be adapted to the health context.<sup>5</sup>

Roma health mediation programs create important links between vulnerable members of the Roma community and physicians. However, existing programs should be changed to better

address the conditions that give rise to health inequities. Health mediation cannot address all of these conditions, which negatively impact not just poor Roma, but all excluded members of society. International mechanisms and donors, as well as national governments should thus fund and create health, social assistance, and education reform programs that comprehensively address social exclusion.

Immediate action is both a moral imperative and pragmatic. The Decade of Roma Inclusion and the process of EU accession entail increased political and financial commitment to Romani health, providing opportunities for program innovation and information sharing, and providing advocacy leverage points for dedicated policymakers and Romani health rights activists.

# Notes

## Executive Summary

1. Population estimate taken from: European Parliament Resolution on the Situation of Roma in the European Union. 28 April 2005. P6\_TA-PROV(2005)0151. <http://www2.europarl.eu.int/omk/sipade2?PUBREF=-//EP//TEXT+TA+P6-TA-2005-0151+0+DOC+XML+Vo//EN&L=EN&LEVEL=2&NAV=S&LSTDOC=Y>

Hereafter, the term “Roma” refers to those who self-identify as such, or to those who may self-identify with groups such as Sinti, Gypsies, Travellers, Ashkalia, Egyptians, Turks, or as a member of the ethnic majority group (Romanian, Bulgarian, etc.), but who face similar problems of social exclusion and discrimination. Roma population estimates provided later in the report reflect this. Population figures were estimated by international organizations, and they include thousands of individuals who did not self-identify as Roma in a census, but who are perceived to be by majority populations. They thus face similar problems of discrimination.

2. See, for example: United Nations Development Program. 2003. *Avoiding the Dependency Trap*; Council of Europe and the European Monitoring Center on Racism and Xenophobia. 2003. *Breaking the Barriers—Romany Women and Access to Public Health Care*. Office for Official Publications of the European Communities: Luxembourg. Others agencies and experts have given larger estimates—from 10–15 million. Azbija Memedova, Roma health expert. Personal communication with the author. 16 May 2005.



3 Plafker, K. 2002. *The Social Roots of Roma Health Conditions*. Available at eumap.org: [www.eumap.org/journal/features/2002/sep02/romhelath/](http://www.eumap.org/journal/features/2002/sep02/romhelath/) Accessed 27 January 2005.

4 Ottawa Charter for Health Promotion. 1986. [http://www.who.int/hpr/NPH/docs/ottawa\\_charter\\_hp.pdf](http://www.who.int/hpr/NPH/docs/ottawa_charter_hp.pdf).

## Introduction

1. Population estimate taken from: European Parliament Resolution on the Situation of Roma in the European Union. 28 April 2005. P6\_TA-PROV(2005)0151. <http://www2.europarl.eu.int/omk/sipade2?PUBREF=-//EP//TEXT+TA+P6-TA-2005-0151+0+DOC+XML+Vo//EN&L=EN&LEVEL=2&NAV=S&LSTDOC=Y>

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3. As cited in: European Commission Directorate-General for Employment and Social Affairs. 2004. *The Situation of Roma in an Enlarged European Union*. Luxembourg: Office for Official Publications of the European Communities: 27.

4. Janecková, L., Rutsch, J., Kroupa, A., Sojka, S. August 2000. The state of health of the Romany population in the Czech Republic. *Central European Journal of Public Health*. Vol. 3, No. 8.

5. Ringold, D., Orenstein, M. A., and Wilkens, E. June 2003. *Roma in an Expanding Europe: Breaking the Poverty Cycle*. World Bank: Washington DC.: 48; Council of Europe & European Monitoring Center on Racism and Xenophobia. 2003. *Breaking the Barriers—Romany Women and Access to Public Health Care*: 15.

6. Plafker, K. 2002. *The Social Roots of Roma Health Conditions*.

7. World Health Organization. 2004. *Report on Tobacco Control in India*: 294. Available at: <http://www.whoindia.org/SCN/Tobacco/Report/03-Chapter-07.6.pdf>.

8. See, for example: Council of Europe & European Monitoring Center on Racism and Xenophobia. 2003. *Breaking the Barriers—Romany Women and Access to Public Health Care*: 107–109; European Commission Directorate-General for Employment and Social Affairs. (2004). *The Situation of Roma in an Enlarged European Union*: 29; Organization for Security and Cooperation in Europe Permanent Council. 27 November 2003. Action Plan on Improving the Situation of Roma and Sinti within the OSCE Area. PC.DEC/566. para. 61(b).

9. Both Romania and the Czech Republic have referred almost exclusively to the mediator program in explaining government responses to health status among poor Roma. After rigorously researching Roma health mediation throughout Eastern Europe, the primary author of this study has seen no reference to any independent evaluations. However, representatives of John Snow International reported that they are assisting the Romanian Ministry of Health in updating the evaluation and monitoring component of their RHM program, which will include an evaluation of the program to date. See also: European Roma Rights Center. Written Comments on the Joint Inclusion Memoranda of Romania. <http://www.errc.org/cikk.php?cikk=117> See the section on health care for a similar discussion of apparent lack of independent evaluation and government officials citing of the mediator program as evidence of government action in the area of Roma health.

10. Interview with Hannah Dobronăuțeanu, Advisor on Roma Issues within the Ministry of Health and Family. 24 March 2005; Interview with Milena Grigorova, Project Management Department, Bulgarian Ministry of Health, and Masha Gavrailova, MD, Head of Department Health Promotion and Diseases Prevention. 29 March 2005.

11. The study team visited Kyustendil and Stara Zagora in Bulgaria, and Bucharest and Piatra Neamt in Romania. Mediators interviewed in Finland were from Helsinki and Imatra.

12. Finland certainly has greater financial resources than the other countries studied. However, elements of its approach to Roma health as well as to intercultural mediation can be applied in Eastern Europe at little cost.

13. At least 2 roundtables with clients and mediators were held in Bulgaria and Romania. Between 5 and 10 individuals were present at each roundtable. Due to the small number of mediators in Finland, mediators and clients were interviewed individually. Health providers (both GPs and specialists) were interviewed only in Bulgaria. Approximately 15 were interviewed or participated in a roundtable.

14. A total of 26 RHM surveys were conducted, and 34 client surveys were conducted.

15. A total of 5 governmental entities and 15 nongovernmental entities were interviewed.

16. The term “Roma health expert” does not refer to someone who is necessarily ethnically Roma, but to individuals who are experts on the health of Roma.

## 1. Mediation Programs in Finland, Romania, and Bulgaria

1. *What is Mediation?* Mediate.com [www.mediate.com/pfriendly.cfm?id=227](http://www.mediate.com/pfriendly.cfm?id=227)
2. Buceanu, M. 2003. *Roma Health Mediators between Necessity and Innovation*. On file with the author.
3. *The Romanyes in Finland*. Finnish National Board of Education. On file with the author.
4. Overall population figure of 5 million taken from Finland entry of the *CIA World Factbook*. <http://www.cia.gov/cia/publications/factbook/geos/fi.html>
5. *The Romanyes in Finland*. Finnish National Board of Education.
6. Finland entry of the *CIA World Factbook*.
7. Finnish National Board of Education. *The History of the Finnish Roma*. <http://www.oph.fi/english/pageLast.asp?path=447:490;15850;15996;15999>.
8. Interview with Unto Jääpuro, Founder and former Director of Ryhdys. 17 March 2005.
9. Both the office and the secretary were shared with the Finnish Romany Association.
10. Mediator Training in 2001–2003, Finland. Finnish National Board of Education. On file with the author.
11. Interview with Janette Grönfors. Romany Education Unit. 17 March 2005.
12. European Commission. More information about Comenius available at: [http://europa.eu.int/comm/education/programmes/socrates/comenius/moreabou\\_en.html](http://europa.eu.int/comm/education/programmes/socrates/comenius/moreabou_en.html).
13. Janette Grönfors, Romany Education Unit; and Päivi Majaniemi, graduate of Cultural Instructor on Romany Culture program. Email communication with the author. 18 April 2005.
14. Finland: Drom-edu Project. Final Report. *Integrating Romany and Travellers' Children in School*. [http://www.dromedu-forum.org/fileet/Drom\\_edu\\_Final\\_report\\_FI\\_uusi.pdf](http://www.dromedu-forum.org/fileet/Drom_edu_Final_report_FI_uusi.pdf).
15. Finland: Drom-edu Project. Final Report. *Integrating Romany and Travellers' Children in School*: 10.
16. Interview with Janette Grönfors, Romany Education Unit. 17 March 2005.
17. Bureau of the Ministry of Social Affairs and Health. 2004. *Finland's Romany People*: 17–18. On file with the author.
18. Interview with Malla Laiti, Delegation for Romany Affairs in the Province of Southern Finland. 18 March 2005.

19. Interview with Päivi Majaniemi, graduate of Cultural Instructor on Romany Culture program. 19 March 2005.
20. Bureau of the Ministry of Social Affairs and Health. 2004. *Finland's Romany People*: 9.
21. Interview with Kalle Kuntsi, Executive Director, and Kathy Metsälä, Social Worker. Romano Missio. 18 March 2005.
22. Finnish National Board of Education. 2000. *The Roma and Health Services: a Guide for Health Care Professionals*. Helsinki: National Board of Education.
23. These conclusions were drawn from the visit to Finland as well as from the Finnish government brochure on Roma in Finland: *Finland's Romany People*.
24. Resource Center for Roma Communities and Open Society Institute EU Monitoring and Advocacy Program and Roma Participation Program. 2004. *Monitoring the Local Implementation of the Government Strategy for the Improvement of the Condition of Roma*: 9.
25. Overall population figure of 22 million taken from Romania entry of the *CIA World Factbook*. <http://www.cia.gov/cia/publications/factbook/geos/ro.html>
26. Romania entry of the *CIA World Factbook*.
27. EUMAP. 2002. Romania entry of: *Monitoring the EU Accession Process: Minority Protection*. Budapest: Open Society Institute: 478.
28. The European Commission is the entity within the European Union that monitors candidate state compliance with EU accession requirements.
29. Commission of the European Communities. 2004. *2004 Regular Report on Romania's Progress Toward Accession*. SEC 2004 1200: 23–31.
30. Interview with Mariana Buceanu, Health Mediation Program Coordinator, Romany CRISS. 24 March 2005.
31. Romanian Ministry of Health and Family. Ordinance No. 619/14. August 2002. Unofficial translation on file with the author.
32. Romanian Ministry of Health and Family. Ordinance No. 619/14.
33. Romanian Ministry of Health. Causes of Public Health Problems Related to Roma Population. On file with the author.
34. Interview with Hannah Dobronăuțeanu, Advisor on Roma Issues within the Ministry of Health and Family. 24 March 2005.

35. Romanian Ministry of Health and Family. Ordinance no. 619/14.
36. Interview with Mariana Buceanu, Health Mediation Program Coordinator, Romany CRISS. 24 March 2005.
37. Roma health mediator roundtable. Piatra Neamt. 21 March 2005.
38. Romanian Ministry of Health and Family. Ordinance No. 619/14.
39. Ibid.
40. Interview with Roxana Marin, Roma rights expert. 20 March 2005.
41. Florin Moisa, Executive Director, Roma Resource Center Cluj. Phone Interview. 26 March 2005.
42. Interview with Georgel Radulescu, Roma health expert. 25 March 2005.
43. Interview with Mariana Buceanu, Health Mediation Program Coordinator, Romany CRISS. 24 March 2005.
44. Interview with Hannah Dobronăuțeanu, Advisor on Roma Issues within the Ministry of Health and Family. 24 March 2005.
45. Romanian Ministry of Health and Family. Ordinance No. 619/14.
46. Interview with Hannah Dobronăuțeanu, Advisor on Roma Issues within the Ministry of Health and Family. 24 March 2005.
47. Interview with Mariana Buceanu, Health Mediation Program Coordinator, Romany CRISS. 24 March 2005.
48. United Nations Development Program. 2003. *Avoiding the Dependency Trap*: 25.
49. Overall population figure of 7.5 million taken from Bulgaria entry in the *CIA World Factbook*. <http://www.cia.gov/cia/publications/factbook/geos/bu.html>
50. Ibid.
51. Bulgarian National Council on Ethnic and Demographic Issues. 2003. Newsletter: 14.
52. Interview with Milena Grigorova, Project Management Department, Bulgarian Ministry of Health, and Masha Gavrailova, MD, Head of Department Health Promotion and Diseases Prevention. 29 March 2005.
53. Commission of the European Communities. 2004. *2004 Regular Report on Bulgaria's Progress Toward Accession*. SEC 2004 1199: 20–25.

54. Interview with Mihail Ivanov, Secretary, National Council on Ethnic and Demographic Issues. 1 April 2005.
55. Interview with Elena Zlatanova, Director, Public Health Program, Open Society Institute Sofia. 28 March 2005.
56. Interview with Dr. Ivaylo Turnev, Director, Ethnic Minorities Health Problems Foundation. 27 March 2005.
57. *Health Mediator Concept*. Open Society Institute Sofia. On file with the author.
58. However, RHMs in both Bulgaria and Romania frequently stated that they helped clients to realize their “health rights.” This almost always referred to obtaining health insurance or the documents needed to visit a doctor.
59. Interview with Dr. Ivaylo Turnev, Director, Ethnic Minorities Health Problems Foundation. 27 March 2005.
60. Interview with Milena Grigorova, Project Management Department, Bulgarian Ministry of Health, and Masha Gavrailova, MD, Head of Department. 29 March 2005.
61. Interview with Elena Zlatanova, Director, Public Health Program, Open Society Institute Sofia. 28 March 2005.
62. Interview with Milena Grigorova, Project Management Department, Bulgarian Ministry of Health, and Masha Gavrailova, MD, Head of Department Health Promotion and Diseases Prevention. 29 March 2005.

## 2. International Policy Context: The Right to Health, EU Accession, and the Decade of Roma Inclusion

1. Constitution of the World Health Organization. [http://policy.who.int/cgi-bin/om\\_isapi.dll?hitsperheading=on&infobase=basicdoc&record={21}&softpage=Document42](http://policy.who.int/cgi-bin/om_isapi.dll?hitsperheading=on&infobase=basicdoc&record={21}&softpage=Document42).
2. CESCR General Comment 14 on “the right to the highest attainable standard of health,” UN Doc. E/C.12/2000/4. para. 12.
3. CESCR General Comment 14 on “the right to the highest attainable standard of health,” para. 12.
4. WHO. Commission on Social Determinants of Health. [http://www.who.int/social\\_determinants/en/](http://www.who.int/social_determinants/en/).
5. Some elements were taken from: Plafker, K. 2002. *The Social Roots of Roma Health Conditions*. Others were taken from: Marmot, M. and Wilkinson, R., eds. 1999. *The Social Determinants of Health*. Oxford: Oxford University Press. Others were suggested by the author.

6. Skenderi, H. 14 April 2005. Illnesses plague camps for displaced communities. *Balkan Crisis Report* No. 551. Brussels: Institute of War and Peace Reporting.
7. Throughout the region, patients are often expected to make unofficial payments to physicians for care, particularly in hospitals.
8. Ottawa Charter for Health Promotion.
9. Ibid.
10. "Tokenism" denotes a dynamic where a small number (or one) member of a disadvantaged group is both stereotyped and silenced by more socially powerful and numerous individuals. In a decision-making setting, tokenism by definition leads to poor and ineffective participation by the token, and a reinforcement of the power imbalance and the stereotypes. This definition is taken from: Kanter, R.M. 1993. *Men and Women of the Corporation*. New York: BasicBooks.
11. Minkler, M., and Pies, C. 1997. Ethical issues in community organization and community participation. In Minkler, M., ed. *Community Organizing and Community Building for Health*. New Brunswick: Rutgers University Press: 27.
12. See: Selener, D., Endara, N., and Carvajal, J. 1999. *Participatory Rural Appraisal and Planning*. Quito: International Institute of Rural Reconstruction. **Community mapping** of household well-being entails community members together drawing a map of the community, including sources of water, food, medical services, education, and so on. The relative well-being of each household is noted, including illness, poverty, and literacy of household members. **Gender disaggregated activity calendars** entail community members jointly making calendars showing the daily tasks of typical men and women from the community, including any seasonal variation. **Problem trees** are formed when community members identify a priority problem, and agree on "limbs" and "branches" of the problem, such as causes, related concerns and so on. These tools allow a truly representative group of the community to agree on widely shared priorities, to explain how these problems are linked with one another, and to identify solutions that take into account community capacities and needs.
13. Office of Disease Prevention and Health Promotion, U. S. Department of Health and Human Services. Health Literacy Factsheet for HHS Employees. [http://www.nidcd.nih.gov/health/education/news/Health\\_literacy\\_fact\\_sheet.pdf](http://www.nidcd.nih.gov/health/education/news/Health_literacy_fact_sheet.pdf).
14. Epstein, R., Franks, P., Fiscella, K., Shields, C.G., Meldrum, S.C., Kravitz, R.L., and Duberstein, P.R. 2005. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Social Science and Medicine*.
15. For more on the difficulties associated with identifying a single set of policy responses to the social exclusion of Roma, see *Roma in an Expanding Europe: Breaking the Poverty Cycle*: 9–10.
16. Fundacion Secretariado General Gitano y Ministerio de Sanidad y Consumo. *Health and the Roma Community: Analysis of Action Proposals*. 13. On file with the author.

17. Fundacion Secretariado General Gitano y Ministerio de Sanidad y Consumo. *Health and the Roma Community: Analysis of Action Proposals*: 7.
18. Ibid. See also UN Social Development Unit. *Roma Communication Channels*. UNDP Bulgaria: 34. On file with the author.
19. UNDP. *Avoiding the Dependency Trap*: 5.
20. Ibid.
21. Fundación Secretariado General Gitano y Ministerio de Sanidad y Consumo. *Health and the Roma Community: Analysis of Action Proposals*: 10.
22. UN Social Development Unit. *Roma Communication Channels*: 11.
23. Piko, B. 1999. Teaching the mental and social aspects of medicine in Eastern Europe: Role of the WHO definition of health. *Administration and Policy in Mental Health*. Vol. 26, No. 6: 435–438.
24. General Practitioner Roundtable. Kyustendil, Bulgaria. 27 March 2005; General Practitioner interviews. Stara Zagora, Bulgaria. 30 March 2005; Interview with Milena Grigorova, Project Management Department, Bulgarian Ministry of Health, and Masha Gavrailova, MD, Head of Department Health Promotion and Diseases Prevention. 29 March 2005; Interview with Hannah Dobronăuțeanu, Advisor on Roma Issues within the Ministry of Health and Family. 24 March 2005.
25. Koupilova, I., Epstein, H., Holcik, J., Hajioff, J., and McKee, M. 2001. Health needs of the Roma populations in the Czech and Slovak Republics. *Social Science and Medicine*. Vol. 53: 1200.
26. One GP interviewed who works an area populated entirely by Roma refuses to work with RHMs. When asked what other ideas she had for improving Roma health, she replied that the mayor or another official should come to the community, command community members to come to a mandatory meeting, and tell them that they must be vaccinated.
27. London School of Hygiene and Tropical Medicine, Open Society Institute, United Kingdom Department for International Development, UNICEF Regional Office for CEE/CIS and Baltic States. 2003. *Healing the Crisis: a Prescription for Public Health Action in South Eastern Europe*: 10.
28. Kickbush, I. 2004. Citizen's rights and community mobilization. In Figueras, J., McKee, M., Cain, J., and Lessof, S., eds. *Winners and Losers; the Consequences of Transition for Health*. European Observatory on Health Systems and Policies: 127.
29. Notion of individual and community response ability taken from: Minkler, M. 2002. Introduction and Overview. In Minkler, M., ed. *Community Organizing and Community Building for Health*. New Brunswick: Rutgers University Press: 4.
30. Grellier, J, and Šoltésová, K. 2004. Health care policy and provision for Roma in Slovakia and the Czech Republic. *Roma Rights*: 3–4. European Roma Rights Center. <http://www.errc.org/cikk.php?cikk=2060>.



31. General Practitioner Roundtable. Kyustendil, Bulgaria. 27 March 2005; General Practitioner interviews. Stara Zagora, Bulgaria. 30 March 2005.
32. All of these countries have estimated Roma populations of at least 10,000.
33. Candidate country negotiations with the EU focus on fulfilling the three “Copenhagen Criteria,” the first of which is to “be a stable democracy, respecting human rights, the rule of law, and the protection of minorities.” See: The Enlargement, the website of the European Union, <http://europa.eu.int/comm/enlargement/>.
34. Hughes, J., and Sasse, G. January 2003. Monitoring the monitors: EU enlargement conditionality and minority protection in CEECs. *Journal on Ethnopolitics and Minority Issues in Europe*. Issue 1/2003. [http://www.ecmi.de/jemie/download/Focus1-2003\\_Hughes\\_Sasse.pdf](http://www.ecmi.de/jemie/download/Focus1-2003_Hughes_Sasse.pdf).
35. Hughes, J., and Sasse, G. January 2003. Monitoring the monitors: EU enlargement conditionality and minority protection in CEECs.
36. Ibid, 17.
37. As cited in Resource Center for Roma Communities & Open Society Institute EU Monitoring and Advocacy Program and Roma Participation Program. 2004. *Monitoring the Local Implementation of the Government Strategy for the Improvement of the Condition of Roma*: 10.
38. Commission of the European Communities. 2004. *2004 Regular Report on Romania's Progress Toward Accession*. SEC 2004 1200: 23.
39. As quoted in Gormley, A., 8 January 2003. Shame of a continent. *The Guardian*.
40. Initiated as part of a southeastern Europe stabilization initiative, CARDS (Community Assistance for Reconstruction, Development, and Stabilization) funds go only to countries of the former Yugoslavia and Albania. Functionally, they are very similar to Phare funds. European Commission. 2001. *CARDS Assistance Program in the Western Balkans-Regional Strategy Paper 2002–2006*. [europa.eu.int/comm/external\\_relations/see/docs/cards/spo2\\_06.pdf](http://europa.eu.int/comm/external_relations/see/docs/cards/spo2_06.pdf).
41. Interview with Milena Grigorova, Project Management Department, Bulgarian Ministry of Health and Masha Gavrilova, MD, Head of Department Health Promotion and Diseases Prevention. 29 March 2005. Information regarding Slovakia's Decade Action Plans. [www.romadecade.org](http://www.romadecade.org).
42. See: EQUAL homepage. [http://europa.eu.int/comm/employment\\_social/equal/index\\_en.cfm](http://europa.eu.int/comm/employment_social/equal/index_en.cfm).
43. See: EQUAL Common Database. <https://equal.cec.eu.int/equal/jsp/index.jsp?lang=en>.
44. Decade of Roma Inclusion Action Plan. Czech Republic. [www.romadecade.org](http://www.romadecade.org).

45. European Commission Directorate-General for Employment and Social Affairs. 2004. *The Situation of Roma in an Enlarged European Union*. Luxembourg: Office for Official Publications of the European Communities: 44.
46. Roxana Marin, Roma Health Expert. Personal communication with the author. 16 May 2005.
47. Janette Gronfors. Personal communication with the author. 28 May 2005.
48. European Commission. DG Health and Consumer Protection. Public Health. Call for Proposals 2005. Programme of Community Action in the field of Public Health (2003–2008). [http://europa.eu.int/comm/health/ph\\_programme/howtoapply/call\\_for\\_proposal\\_en.htm](http://europa.eu.int/comm/health/ph_programme/howtoapply/call_for_proposal_en.htm).
49. Ibid, para. 18.
50. Decision No. 1786/2002/EC of the European Parliament and of the Council of 23 September 2002 adopting a program of community action in the field of public health. Para. 6. Official Journal of the European Communities L 271/1. Emphasis added.
51. European Commission. DG Health and Consumer Protection. Public Health. Call for Proposals 2005. Programme of Community Action in the field of Public Health (2003–2008).
52. European Commission. DG Health and Consumer Protection. Public Health. List of projects funded in 2004. [http://europa.eu.int/comm/health/ph\\_projects/2004/action3/action3\\_2004\\_sum\\_en.htm](http://europa.eu.int/comm/health/ph_projects/2004/action3/action3_2004_sum_en.htm).
53. The action plans are drafts because they have not yet been adopted by the national governments. However, it is unlikely that the content of the plans will change prior to adoption.
54. Decade of Roma Inclusion Action Plan. Czech Republic. [www.romadecade.org](http://www.romadecade.org)
55. Slovakia has allocated 32,508,000 SKK (about €839,000) to the Health Assistants Program, out of a total of 38,208,000 SKK (about €986,000) for the health action plan. Decade of Roma Inclusion Action Plan. Slovakia. [www.romadecade.org](http://www.romadecade.org)
56. Direct limitations may entail limited access to health services. Indirect limitations may entail the negative health impacts of exclusion or discrimination in other sectors, such as education and the labor market.
57. “Positive Measures” are measures that prevent or compensate for disadvantages linked to racial or ethnic background. Affirmative action is one example.
58. Points 2–5 were taken from: Council of Europe and European Monitoring Center on Racism and Xenophobia. 2003. *Breaking the Barriers—Romany Women and Access to Public Health Care*: 94–98. “Ethnic, racial, and social” and “direct and indirect” limitations were added to point 2 by the author. “Patient’s rights” was added to point 4 by the author. Points 1 and 6–9 were developed by the author.

59. Council of Europe and European Monitoring Center on Racism and Xenophobia. 2003. *Breaking the Barriers—Romany Women and Access to Public Health Care*: 32.
60. Dzeno Association. Dzeno comments on the Decade of Roma Inclusion. 2 February 2005. [www.dzeno.cz/?c\\_id=672](http://www.dzeno.cz/?c_id=672)
61. Florin Moisa, Executive Director, Roma Resource Center Cluj. Phone Interview. 26 March 2005.
62. Elena Zlatanova, Public Health Program Director, Open Society Institute, Bulgaria. Interview. 28 March 2005. Silviya Filipova, Coordinator, Pakiv European Roma Fund, Bulgaria. Interview. 28 March.
63. Beata Olahova, Project Manager, League of Human Rights Advocates and Legal Monitor, European Roma Rights Center. Phone Interview. 10 April 2005.
64. Silviya Filipova, Coordinator, Pakiv European Roma Fund, Bulgaria. Interview. 28 March.
65. Aleksandra Jovic, MD, former Service Programme Coordinator, Oxfam Belgrade. Phone interview. 10 May 2005.
66. See Action Plan of Montenegro. [www.romadecade.org](http://www.romadecade.org).
67. *Breaking the Barriers—Romany Women and Access to Public Health Care*: 94; See also: European Parliament Resolution on the Situation of Roma in the European Union. 28 April 2005. P6\_TA-PROV(2005)0151. <http://www2.europarl.eu.int/omk/sipade2?PUBREF=-//EP//TEXT+TA+P6-TA-2005-0151+0+DOC+XML+V0//EN&L=EN&LEVEL=2&NAV=S&LSTDOC=Y>.
68. Slovakia states that discrimination is a cross-cutting theme related to some health activities, but gender and poverty are also mentioned throughout, and the ways these themes are related to activities is far from evident.
69. See the Action Plans of all countries noted at [www.romadecade.org](http://www.romadecade.org).
70. Ibid.
71. See Bitu, N. 18 January 2005. *Report to the Steering Committee on the Decade of Roma Inclusion*. OSI Network Women's Program. [http://www.soros.org/initiatives/women/articles\\_publications/articles/bitu\\_20050118](http://www.soros.org/initiatives/women/articles_publications/articles/bitu_20050118).
72. The idea that traditional analyses focus on fertility and infectious disease is taken from: Koupilova, I., Epstein, H., Holcik, J., Hajioff, S., and McKee, M. 2001. Health needs of the Roma population in the Czech and Slovak Republics. *Social Science and Medicine*. Vol 53: 1200.
73. Peacock, D. *Men as Partners: South African Men Respond to Violence Against Women and HIV/AIDS*. New York: Engender Health. 34.

74. Tamsma, N., Berman, P.C. 2004. The role of the health sector in tackling poverty and social exclusion in Europe. *European Health Management Association and EuroHealthNet*: 48–49. [www.eurohealthnet.org/Eurohealthnet/documents/Social%20Exclusion/EHMA%20Report.pdf](http://www.eurohealthnet.org/Eurohealthnet/documents/Social%20Exclusion/EHMA%20Report.pdf)

### 3. Components of Health Effectively Addressed by Mediators in Bulgaria, Finland, and Romania

1. It is important to note again that none of these programs have been independently or comprehensively evaluated, so these conclusions of success are based on anecdotal evidence and personal observations on the part of those participating in this study.

2. Other obstacles not mentioned here were identified with equal frequency and are discussed later in the report.

3. The questionnaire assessed the frequency of several situations during doctor/patient interactions. Many, including all of those mentioned here, were taken from a previous study of intercultural mediation in Belgium. See: Nierkens, V., Krumeich, A., de Ridder, R., and van Dongen, N. 2002. The future of intercultural mediation in Belgium. *Patient Education and Counseling*. Vol. 46: 253–259.

4. Brief about the Roma related aspects. Romanian Ministry of Health. On file with the author.

5. Ibid.

6. General practitioner roundtable, Kyustendil, Bulgaria. 27 March 2005. General practitioner and nurse interviews, Stara Zagora, Bulgaria. 29 March 2005.

7. Piatra Neamt roundtable.

8. Mediators in Piatra Neamt reported that they encountered this “sometimes.”

9. Interview with mediator. 5 March 2005. Jyväskylä City.

10. A client at the Piatra Neamt roundtable explained that a mediator had gone to the doctor in her place, as she was too ill to go. Many clients who were interviewed or participated in roundtables explained that when the mediator is present, they do not speak at all. They mediator may go into an appointment with social authorities or a doctor before the client, explain the situation, and then call the client in.

11. Banu, E., Rosin, A., and Buceanu, M. 2004. *Guide for Sanitary Mediator*. Romany CRISS. On file with the author.

12. Interview with Alka Dev, Program Manager, Doctors of the World. 10 March 2005.

13. Interview with Dr. Elena Kabakchieva, Chair, Health and Social Development Foundation. 1 April 2005.

14. Open Society Institute Network Women's Programs. 29 June 2003. Roma Women's Forum. Excerpted Presentations. <http://topics.developmentgateway.org/gender/rc/filedownload.do-itemId=382490> 41.

15. Ebeling, S. Lessons and tips for addressing health literacy issues in a medical setting. 2003. Harvard School of Public Health: Health Literacy Website. <http://www.hsph.harvard.edu/healthliteracy/insights.html>

16. RHM roundtables; Interview with Sophia Brewer, Program Coordinator, and Dr. Mercè Gascó, Chief of Party, John Snow International (JSI) Research and Training Institute. 23 March 2005. To involve RHMs more in health program planning, JSI has made it a stipulation of its small grants program that applicants involve RHMs.

#### 4. What Current RHM Programs Do Not Address

1. See: *Breaking the Barriers—Romany Women and Access to Public Health Care*: 41–50; Turnev, I., Kamenov, O., Popov M., Makaveeva L., and Alexandrova, V. 2002. *Common Health Problems among Roma—Nature, Consequences and Possible Solutions*. Sofia: Open Society Foundation. 6–11; European Roma Rights Center. 2003. Eleven Romany women refused birth allowance in Romania. [www.errc.org/cikk.php?cikk=1090&archiv=1](http://www.errc.org/cikk.php?cikk=1090&archiv=1); European Roma Rights Center. 2004. Roma refused medical treatment in Romania. [www.errc.org/cikk.php?cikk=1879&archiv=1](http://www.errc.org/cikk.php?cikk=1879&archiv=1); Izsák, R. 2004. Gypsy rooms and other discriminatory treatment against Romany women in Hungarian hospitals. *Roma Rights*. No. 3–4. <http://www.errc.org/cikk.php?cikk=2060>; Antic, P. 2005. *Roma and the Right to Health Care in Serbia*. Belgrade: Minority Rights Center; Center for Reproductive Rights and Poradna. 2004. Supplementary information on Slovakia scheduled for review by the United Nations Committee on the Elimination of Racial Discrimination during its 65th Session. [http://www.crlp.org/pdf/pdf\\_ww\\_CERDletter2.pdf](http://www.crlp.org/pdf/pdf_ww_CERDletter2.pdf)

2. Supplementary information on Slovakia scheduled for review by the United Nations Committee on the Elimination of Racial Discrimination during its 65<sup>th</sup> Session.

3. Far fewer clients in Finland mentioned discrimination at all, and those who did, explained that discrimination was not a problem for them if a mediator was present.

4. RHM client roundtable. Piatra Neamt. 21 March 2005.

5. Interview with Hannah Dobronăuțeanu, Advisor on Roma Issues within the Ministry of Health and Family. 24 March 2005.

6. This is not to say that mediation should be discarded because it cannot effectively eliminate or remedy the substantial power difference between a health provider and a patient. Indeed,

as Eastern Europe becomes a more frequent destination for refugees and immigrants, health and social authorities may want to consider designing mediation programs that can eventually serve these populations.

7. RHM client roundtable, Stara Zagora. 29 March 2005.
8. RHM client roundtable, Bucharest. 24 March 2005.
9. Ibid.
10. RHM mediator roundtable, Stara Zagora. 29 March 2005.
11. Florin Moisa, Executive Director, Roma Resource Center Cluj. Phone Interview. 26 March 2005; Elena Zlatanova, Public Health Program Director, Open Society Institute, Bulgaria. Interview. 28 March 2005. Silviya Filipova, Coordinator, Pakiv European Roma Fund, Bulgaria. Interview. 28 March.
12. ECRI. 2003. *Third Report on Bulgaria. Situation of the Roma Community in Bulgaria*. [http://www.coe.int/T/E/Human\\_Rights/Ecri/1-ECRI/2-Country-by-country\\_approach/Bulgaria/Bulgaria\\_CBC\\_3.asp#P480\\_54853](http://www.coe.int/T/E/Human_Rights/Ecri/1-ECRI/2-Country-by-country_approach/Bulgaria/Bulgaria_CBC_3.asp#P480_54853).
13. Commission of the European Communities. 2004. *2004 Regular Report on Romania's Progress Toward Accession*. SEC 2004 1200: 23–31.
14. Freimuth, V.S., Quinn, S.C., Thomas, S.B., Cole, C., Zook, E., and Duncan, T. 2001. African Americans' views on research and the Tuskegee Syphilis Study. *Social Science and Medicine*. Vol. 52: 797–808.; Shavers, V., Lynch, C., and Burmeister, L. 2002. Racial Differences in Factors that Influence Willingness to Participate in Medical Research Studies. *Annals of Epidemiology*. Vol. 12. No. 4: 248–256.
15. Romanian Ministry of Health. *Causes of Public Health Problems Related to Roma Population*. On file with the author.
16. Health provider roundtable. Kyustendil. 27 March 2005.
17. Boyan Zahariev, Roma Health Expert. Personal communication with the author. 10 April 2005. Roxana Marin, Roma Health Expert. Personal communication with the author. 8 April 2005.
18. United Nations Development Program. *Avoiding the Dependency Trap*. 4.
19. Mastilica, M., Bozikov, J. 1999. Out of pocket payments for health care in Croatia: Implications for equity. *Croatian Medical Journal*. Vol. 40, No. 2.
20. Environmentally and Socially Sustainable Development Social Development Team, Europe and Central Asia. March 2002. *Social Development in Europe and Central Asia Region: Issues and Directions*. Washington D.C: World Bank. 7. On file with the author.

21. As cited in *Monitoring the EU Accession Process: Corruption and Anti-corruption Policy*. Budapest: Open Society Institute: 454.
22. Ibid. 463.
23. *Bulgaria News Digest*. 29 July 2004. Factiva online database.
24. Falkingham J. (2004). Poverty, out-of-pocket payments and access to health care: evidence from Tajikistan. *Social Science and Medicine*. Vol. 58, No. 2: 247.
25. Interview with Alka Dev, Program Manager, Doctors of the World. 10 March 2005.
26. Interview with Tzveta Pekova, Program Coordinator, Roma Programs. Open Society Institute Sofia. 1 April 2005.
27. Overall population figure of 7.5 million taken from Bulgaria entry in the *CIA World Factbook*. <http://www.cia.gov/cia/publications/factbook/geos/bu.html>
28. Boyan Zahariev, Roma health expert. Email communication with the author. 10 April 2005.
29. Interview with Milena Grigorova, Project Management Department, Bulgarian Ministry of Health, and Masha Gavrailova, MD, Head of Department Health Promotion and Diseases Prevention. 29 March 2005.
30. Cohen, B. 2005. Positive obligations: Shifting the burden in order to achieve equality. *Roma Rights Quarterly*. No 1. 2005: 5.
31. Medecins Sans Frontières spearheaded a joint NGO proposal to have municipalities cover the costs of health insurance fund payments for the poorest, but this was met with little response from the government. Interview with Dr. Elena Kabakchieva, Chair, Health and Social Development Foundation. 1 April 2005.
32. Interview with Sophia Brewer, Program Coordinator, and Dr. Mercè Gascó, Chief of Party, JSI Research and Training Institute. 23 March 2005.
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34. Council of Europe and the European Monitoring Center on Racism and Xenophobia. *Breaking the Barriers—Romanian Women and Access to Public Health Care*.
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## 5. Conclusions and Recommendations

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# Open Society Institute Public Health Program

The Open Society Institute's Public Health Program aims to promote health policies based on scientific evidence, social inclusion, human rights, and justice. The program works with local, national, and international civil society organizations to combat the social marginalization and stigma that lead to poor health, to facilitate access to health information, and to foster greater civil society engagement in public health policy and practice.

[www.soros.org/initiatives/health](http://www.soros.org/initiatives/health)

## Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. Open societies are characterized by the rule of law; respect for human rights, minorities, and a diversity of opinions; democratically elected governments; market economies in which business and government are separate; and a civil society that helps keep government power in check.

To achieve its mission, OSI seeks to shape public policies that assure greater fairness in political, legal, and economic systems and safeguard fundamental rights. On a local level, OSI implements a range of initiatives to advance justice, education, public health, and independent media. At the same time, OSI builds alliances across borders and continents on issues such as corruption and freedom of information. OSI places high priority on protecting and improving the lives of marginalized people and communities.

Investor and philanthropist George Soros in 1993 created OSI as a private operating and grantmaking foundation to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to encompass the United States and more than 60 countries in Europe, Asia, Africa, and Latin America. Each national foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

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