

Summary

The OSI Seminar entitled: *projects and policies to impact Romani health most effectively* was convened at the initiative of the Open Society Institute's (OSI) Network Public Health Programs and the Romanian National Agency for Roma on the occasion of Romania's hosting the Decade of Roma Inclusion. The Seminar served to launch a recently completed OSI study of Romani health mediation (RHM) programs, and to discuss governmental and NGO efforts and responsibilities in the field of Romani health more generally.

The conference was attended by national and international NGO representatives, governmental representatives from Ministries of Health and/or the national offices tasked with Roma issues, local level health workers and authorities, donors, international governmental organizations, and independent experts. The conference aimed to facilitate open discussion about current programs addressing Romani health and ways in which governments, NGOs, and donors could improve their programming and cooperation in the context of the Decade of Roma Inclusion.¹ Given this, attendance by governmental representatives and the donors who will most likely be funding Decade activities was very important.

Unfortunately, only Romania and Slovakia were represented at the governmental level. Romania in particular demonstrated high level commitment to the Decade by hosting the conference and sending representatives from several pertinent agencies, including the Ministry of Health, the National Health Insurance Agency, the National Agency for Roma, and local public health offices. This active participation increased the expertise of the Romanian governmental officials who attended, as well as the expertise of governmental representatives from elsewhere, who learned from Romania's experiences. Romanian governmental participation also demonstrated to attending NGOs and international organizations that the Romanian government is committed to implementing quality Romani health programming. Governments who did not attend missed an opportunity to learn from their colleagues in other Decade countries and to enhance their programming. Moreover, their lack of participation communicated a worrying lack of dedication to the principles and necessity of the Decade.

The Decade is not a new funding mechanism, but is a framework. Governments should reallocate existing resources in national budgets and align these plans with the funding instruments of multinational, international, and bilateral donors to fund Decade activities. The most pertinent donors are the primary international agency sponsors of the Decade: OSI, the World Bank, the European Commission, the United Nations Development Program, the Organization for Security and Cooperation in Europe, the Council of

¹ The Decade of Roma Inclusion was launched as an effort to focus donor funds on Romani issues. The Decade is sponsored by governments and international governmental and non-governmental agencies. In February 2005, the Decade was launched in eight Eastern European countries: Bulgaria, Croatia, 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 3 cross-cutting themes: (1) income poverty, (2) discrimination, and (3) gender.

Europe, and the Council of Europe Development Bank. Unfortunately, only representatives of OSI, the World Bank in Romania, and the Council of Europe attended the conference. The absence of attendees from the European Commission was particularly worrying, as their funding mechanisms (most notably PHARE) have provided the bulk of outside monies to support Romani health projects in the Decade countries. They are also identified as likely donors for Romani health projects in several Decade action plans.

The conference focused on three major subject areas/themes: (1) Romani health mediator programs, (2) Romani inclusion in the health system, and (3) current and best practices in Roma health. A panel of diverse presenters discussed their work in relation to each theme. These panels were followed by small break out groups, where participants attempted to come up with concrete actions for their work that related to the themes. Discussion moved back and forth from theory to existing policies and programs.

Health Mediation

Summary and analysis of a panel on “Health mediators between necessity and innovation.”

OSI; Romani Criss (the NGO implementer of the Romanian Romani Health Mediator Program); the Romanian Ministry of Health; and a Bulgarian NGO, the Ethnic Minorities Health Problems Foundation; presented their work relating to Romani Health Mediators. A representative from the Council of Europe Group of Experts on Roma, Gypsies, and Travellers also presented recently developed draft recommendations for Roma access to health care.

Each presenter provided a different perspective on Romani health mediation – ranging from governmental, to a Roma-run NGO, to an NGO with little Roma representation, to a health and human rights perspective.

The OSI study was conducted from a public health and human rights perspective. The study concluded that despite limitations in continuing education, supervision, and support for mediators, Romani health mediation has achieved substantial benefits in increasing Roma access to health insurance, vaccination, antenatal care, and other health services. However, in some cases, the program has the negative impact of filling gaps in physician and health worker practice, rather than addressing root difficulties in Roma patient/doctor interactions. Moreover, health mediation programs alone are not sufficient to address the health needs of poor Roma. 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) Romani health mediation programs; (b) National Action Plans for Roma health; and, (c) national strategies for health reform, social inclusion, minority rights, and women’s and youth empowerment.

The Council of Europe Experts Group draft recommendations for Roma access to health care were developed based on many of the same premises that were used in the OSI

study, including protection of human rights and autonomy, patient's rights, equity, and Roma participation. The recommendations look at policies from the macro to the micro level, recognizing that mediation is much more effective in the framework of strong anti-discrimination legislation, an established patient's rights mechanism, and a system of low-cost health care access for poor populations.

Many presenters brought up the issue of equal rights and/or special measures during this and other panels. The concept of equal rights foresees that all populations should have equal rights to access a particular service. Implementing special measures, on the other hand, suggests that certain populations require programs or policies that will compensate for past and ongoing disadvantage. According to the concept of special measures, equal rights are not enough in the face of structural inequality. Many NGOs and representatives of OSI attending the conference opined that special measures are required to improve Roma health. If they included financial assistance for clients, facilitated access to health care providers, or other elements, Romani health mediation programs could be one such special measure.

The Council of Europe recommendations, however, are more conservative in their assessment of Roma status and state responsibility. They attribute the generally inferior Romani health status to 'living conditions,' (as opposed to living conditions and entrenched discrimination). They also state that Roma shall receive "the same medical care as other persons with the same type of status," suggesting that no special measures are warranted for any especially vulnerable groups.

Both the Romanian Ministry of Health and a Bulgarian NGO, the Ethnic Minorities Health Problems Foundation, described the operation and impact of their programs. The rationale behind the initiation of Romani health mediation was similar in both countries. Key differences include the size, measurable impact, and implementer of the respective programs. There are a total of approximately 10 mediators in Bulgaria, and over 200 in Romania. The program in Romania is run at the national level and some monitoring and evaluation have been in place from the program's initiation. This monitoring has shown impact in terms of increased vaccination rates, increased rates of women receiving antenatal care, and increased numbers of Roma with health insurance.

In contrast to Romania, Romani health mediation in Bulgaria has been undertaken by a consortium of organizations, some of which specialize in Romani health issues, and others that specialize in public health more generally. The Bulgarian presenter emphasized the selection process for mediators, which were consistent with the Council of Europe draft recommendation insistence on community participation. Mediators in Bulgaria were selected by a panel of members of several NGOs and by volunteer community members.

The Roma NGO responsible for training and supporting Romanian Romani Health Mediators, Romani Criss, expanded the discussion by highlighting the need for qualitative as well as quantitative evaluation, and by underlining some barriers to RHM success. These barriers include: lack of adequate funding for travel and other activities,

lack of monitoring by local public health directorates, and inaccurate perception of the RHM role by members of the community and by medical personnel.

Health Systems and policies: the challenge of adequate inclusion

Summary and analysis of panels on:

- *Health and gender intersection: Romani women's health in the context of multiple discrimination and exclusion*
- *Roma at the intersection of other vulnerable groups*
- *Health systems and cultural sensitivity: tackling prejudices and discrimination against Roma*

How can governments best ensure health system inclusion for ethnic minorities? How can they ensure that groups that are doubly marginalized – such as Romani women, Romani sex workers, and Romani drug users, among others – benefit equally from governmental efforts to improve Romani health status? How can programs address the double stigma inherent in being a member of the Roma and another stigmatized community?

A representative of WHO's Special Rapporteur on the Right to Health started the discussion at the macro level by presenting a framework for looking at governmental responsibilities in fulfilling the right to health for all citizens. She first emphasized the need for disaggregated data; governments should identify vulnerable groups, such as the Roma, and then collect data relating specifically to this group. This sparked some controversy among conference attendees, as some pointed out that disaggregated data has been used to further stigmatize Roma communities in the past. Some were still opposed to government's collecting data in Roma communities. They stated that many Roma communities do not trust the government, in part because governments have not done enough to earn that trust. Regardless, all agreed that any data collection process should be lead by Roma themselves.

The WHO representative went on to outline indicators that are required to monitor government actions and results relating to the right to health. These indicators included structural (law and policy), process (whether or not laws and policies are implemented), and outcome (whether or not these policies effectively improve Roma health).

Discussion then moved to the micro level – Romani health programming in communities. One Roma NGOs utilized its field experience to emphasize the need for disaggregated data by explaining the particular disadvantage of Roma women. As a population, Roma women have poorer health and other indicators than women from majority populations, as well as than Roma men. For example, Roma women in Macedonia have higher rates of illiteracy than Roma men, as well as a younger average age of marriage and first pregnancy than Macedonian ethnicity women. Rather than lessening this disadvantage, in some cases, the health system exacerbates Roma women's subjugation. The NGO Drom, for example, reported a case of a Roma woman in Macedonia who was given such poor gynecological care that could have died. The NGO believes that neither a Roma man nor a Macedonian ethnicity woman would have been given such sub-standard care.

So, using the Special Rapporteur's right to health framework, while the structures may be in place in Macedonia for decent and equitable gynecological care, the required processes for the realization of that right were not fulfilled, resulting in negative outcomes. In this case, the state health service put the life of a Roma woman patient in danger, and she did not have any widely known avenues for filing a complaint or seeking a remedy. While the state may have fulfilled its obligation to create a patient complaints mechanism, it failed in its obligation to ensure that all patients know about and are able to use the mechanism.

Other NGOs reported on their work with particularly vulnerable members of the Roma minority, such as street children and drug users. These presenters discussed the multiplicity of structural factors and identities that can shape Roma vulnerability to ill health. For example, the Bulgarian, NGO, Health and Social Development Foundation, explained that Roma are over-represented in many so-called 'vulnerable groups,' such as sex workers, street children, school drop outs, drug users, and ex-prisoners. The representative of this NGO argued that, in contrast to a mediator model, Roma should be trained as social workers to deliver services, rather than to facilitate access to services targeting the majority population. If using a comprehensive approach that includes different modes of delivery (outreach, peer education, referral, and so on) then Roma service providers can improve the health and social status of their community.

This model recognizes the value of Roma participation and programs that are appropriate to Roma culture and socio-economic status. However, it also risks resulting in ghettoized programs that further marginalize the Roma population.

Other presenters illuminated how they work directly with marginalized groups. The Romanian NGO, ARAS, targets many groups vulnerable to HIV, rather than Roma *per se*. However, ARAS staff people have learned to assist Roma in negotiating particular barriers to medical care. Roma who are in so-called 'high risk' groups for HIV, for example, are less likely to have documentation or health insurance than other sex workers and intravenous drug users.

While some panelists highlighted the importance of identifying and working with doubly marginalized Roma groups, others highlighted the dangers inherent in simply stating that Roma are disproportionately represented among stigmatized groups. Irresponsible public discourse equating sex work or intravenous drug use with Roma ethnicity will feed stereotypes and discriminatory behavior. So, discussions about Roma representation in stigmatized groups should be responsible, accurate, and led by Roma. At the same time, strong anti-discrimination laws and policies as well as remedies for discrimination must be in place to prevent and address discrimination.

To provide a concrete example of national anti-discrimination legislation, a Finnish Roma activist presented the laws and policies currently in place in Finland. While the current legislation does not yet meet the standards set by the EU Race Equality Directive, the laws and policies are advanced insofar as they address several angles of

discrimination. There is a fairly comprehensive anti-discrimination clause enshrined in the Finnish Constitution, a national Ombudsperson Against Ethnic Discrimination, and entities within the Ministries of Education and Health and Social Affairs to promote equal opportunities and programming for Roma specifically.

The above described discussions of individual health entitlements, state responsibility in ensuring the progressive realization of the right to health, grassroots NGO work, and national anti-discrimination legislation demonstrated the need for several tacks to ensure Roma inclusion. Community-level programming must acknowledge the context in which Roma live. For example, Roma women may need to overcome prejudices within their own community to realize their reproductive rights. Roma commercial sex workers may be denied community support by both the Roma community and the sex worker community because of their stigmatized status. Programs must be informed by the needs articulated by these individuals. At the same time, initiatives to meet special needs cannot be effective without structural support. Anti-discrimination legislation and state activity must create a framework for the inclusion of everyone into health services.

Romani Health Programming in Countries

Summary and analysis of panels on:

- *Updates from national governments*
- *Partnerships between governments and civil society for Roma health within and beyond Health Mediator programs*
- *How can doctors and mediators work together for Roma health empowerment?*
- *How to ensure an accurate reflection of their health status and access to health care when collecting data on Roma*

As noted, apart from Romania, only one government sent a representative – Slovakia. The Slovak participant started by presenting the Roma Field Health Workers Program. (Field Health Workers are essentially the same as Romani health Mediators, with one major difference – Field Health Workers are not necessarily Roma). The program is the key element of Slovakia's Decade Health Action Plan, with 85% of all Decade health funds allocated to the Field Health Worker program.

Using PHARE funds, the program began in 2005 at the pilot level, with 8 Field Health Workers covering 59 villages. The program aimed to increase vaccination rates and doctor visits. Field Workers provided health education, communicated with health authorities, and assisted physicians in their interactions with Romani clients. The presenter explained that this initiative was created in the larger framework of Slovak health reform, which included increased flexibility of the health system, financial protection from catastrophic health care costs, and increased individual responsibility for health status. As of December 2005, the Ministry of Health had not yet secured funds for program continuation or scaling up.

This presentation spurred an unusually high number of questions from the audience. A few were quick to point out the low number of mediators in Slovakia. Others, however, voiced support for the Slovak government insofar as they sent a representative to the

conference, unlike most other Decade countries. Many were bothered by the seemingly paternal approach of both the Field Health Workers program and the presentation. Major concerns about the program included the fact that Roma were perceived as targets for behavior change, rather than as partners in health promotion; and the fact that not all Field Health Workers were Roma. Participants felt that since Romani Health Mediators (or Field Health Workers) aimed to increase Roma trust in the health system, they should be members of the Roma community themselves. Concerns about the presentation included the assumptions and language employed by the presenter, such as indications that Roma did not use soap because they did not know how, rather than that they could not afford it.

Following the Slovak presentation, NGO representatives explained how they had implemented RHM programs in cooperation with the government. The Director of YUROM-Nis, a Roma organization from Serbia, outlined how he began a RHM program that is now funded entirely by the local government. Even though it was initially funded by OSI, rather than government, YUROM worked closely with local health authorities in designing the program, which requires close cooperation between community health nurses and mediators. Following community assessments by mediators, community nurses make home visits to educate pregnant women and families with other health concerns. Those requiring further attention are referred to a primary health care center, or accompanied to a Center for Social Work (to address issues relating to health insurance and documentation).

Attendees were particularly interested in learning how YUROM was able to garner the cooperation of the local health authorities, as well as the political commitment to fund the program following the first year of pilot implementation. The Director explained that he is a member of the local self-government, and that he has been working with local authorities on health and social issues for several years. Participants commented on the importance of Roma political participation and representation; exerting some control over political processes ensures that Roma concerns are heard. In some cases, ensuring that elected Roma really represent the needs of their constituents is a further challenge.

The Bulgarian NGO, World Without Borders, went on to describe how they worked with the local government. In contrast to the preceding presentation, World Without Borders described some of the obstacles to cooperation between NGOs and the local government. These included lack of clear protocols for NGO/local government cooperation, lack of government trust in civil society, partisan interference, bureaucracy, and corruption. World Without Borders overcame this in part through dedicating ample time to meeting with and convincing local government and health officials of the importance of their work. The use of volunteers also demonstrated that World Without Borders was not seeking funds, but looking to improve Romani health status. Finally, the sharing of detailed program information further demonstrated that World Without Borders did not have ulterior motives. The presenter was confident that future work would be easier, as the local authorities now trusted World Without Borders staff and the NGO's overall intentions. However, unfortunately, World Without Borders has few means to decrease bureaucracy, corruption, and partisan interference.

The following presentations were even more specific, in that they focused on the efficacy of health mediation programs. How can doctors and mediators work together for Romani health empowerment? The primary author of the OSI Romani Health Mediator study presented her findings related to mediation and health empowerment. She started by explaining that there is a general lack of health empowerment and awareness in poor Roma communities; Roma do not feel that they can effectively influence their own health, and they perceive health as merely the absence of disease. As a result, mediator assistance is generally sought only in the event of illness. For their part, physicians and the health system also often define health as the absence of disease, believe that health is determined by individual (as opposed to social) actions, and do not have a patients' rights perspective. The use of RHM's may exacerbate these problems; physicians may become dependent on mediators to explain health issues to Roma clients, and they may fail to thoroughly explain diagnosis or treatment options to the patient. Roma clients may stop trying to speak directly to the doctor, and may instead communicate only with the RHM. In fact, some mediators consulted during the study described their role as 'speaking for the patient,' and some reported even having gone to the doctor without the patient.

OSI concluded that current RHM trainings should be updated and reoriented to include patient health literacy and empowerment as explicit goals. Insofar as possible, physicians should be involved in program design and trainings so that they also understand the importance of Romani health empowerment.

A representative of Doctors of the World, an international NGO working in Romania, went on to ask provocative questions about mediation. Have mediators improved access and quality of care for Roma? Do physicians, NGOs, and governmental agencies understand the RHM role? How are RHM's supported or prevented from doing their work? Are mediators a bridge or a barrier to improved health status? He did not answer these questions, but voicing them stimulated much discussion and debate during coffee breaks. Participants appreciated the frank assessment of the major questions to be answered.

The final presentation questioned how data collection could accurately reflect Romani health status. While governments in the region do collect health statistics, these statistics are not disaggregated by ethnicity. So, any existing Roma-specific data is collected by NGOs or as part of special local level initiatives. A representative of the European Roma Rights Center explained that existing data indicates that there are substantial health disparities between Roma and non-Roma. These disparities exist even when poverty is taken into account, suggesting that there are significant differences in terms of access, quality, and timing of the health care services received by Roma and non-Roma. Much of the health status statistics that do exist focus exclusively on aspects that are perceived as Roma threats to public health, such as infectious disease and 'over population.' There are no data, however, on access and quality of health care. Little is known about the relationship between health providers and Romani patients; about the access Roma have to specialized care; the prevalence of malpractice toward Romani patients as opposed to non-Romani patients and so on. The panelist concluded that governments should develop

relevant policy indicators to reflect access to and quality of health care. These indicators should be disaggregated by ethnicity and gender, so that disparities along ethnic and gender lines are measurable.

Facilitated break-out groups occurred after these presentations. The break out groups varied in their conclusions. Some groups developed specific principles or changes for their work in light of the presentations, others identified obstacles or enablers to practice changes, and still others described additional problems that must be addressed. All groups developed recommendations and conclusions. The following section does not identify all of the points and conclusions developed the break-out groups developed, but instead identifies common points and themes.

Break-out Session 1 - Health and gender intersection: Romani women's health in the context of multiple discrimination and exclusion

The groups first identified the major problems – both those that had been identified during the panels and those that they had encountered in their own work. Broadly, participants agreed that Romani women's health was a difficult problem due to: the taboo nature of many of the issues involved, lack of health and health rights knowledge among Romani women, sub-standard care provided by physicians, discrimination, income poverty, and prevailing beliefs that women should first ensure the health of their family rather than their own health.

Who is responsible for these problems, and who bears the responsibility for rectifying them? Many stakeholders were identified, including the Ministry of Health (especially the Health Insurance Fund), Parliament, the Ministries of Home Affairs and Education, Directorates of Public Health, the College of Physicians, NGOs, Roma community leaders, Romani Health Mediators, and municipalities.

What should advocates ask these actors to do? What changes need to be made? Suggested actions are of course many and wide in scope. This is because poor health status among Romani women is due to a web of interlocking political, cultural, and social factors. Health status is not only bio-medically determined, and actions to improve health must address the structures and social mores implicated in Romani women's health. The most common actions groups identified related to both policies and programs. From the national to the local and program level, some of these actions included: educating national policy-makers, passing a strong anti-discrimination law, legislating Romani women's participation in health policy-making, improving health insurance law, involving Romani women in national gender equity programs, creating a patient's rights body with a robust and publicized complaints mechanism, providing further training to RHMs, raising awareness among male and female members of the Roma community, and lobbying for the funding of all these initiatives.

Break-out Session 2 – Roma at the intersection of other vulnerable groups

One group elected to first identify especially vulnerable groups among the Roma population, and then to provide recommendations relating to tailored interventions. They identified many groups, some of which had not been mentioned in the earlier panels. These included: children, women, drug users, commercial sex workers, men who have sex with men, women who have sex with women, the unemployed, those lacking health insurance, people living with physical or mental disabilities, persons with chronic diseases, displaced people, refugees, migrants, elderly, pregnant women, prisoners, and people who have been trafficked.

The other group adopted a very different approach, having a lively debate about the benefits of mainstreaming versus targeting. The group finally concluded that both were necessary. Roma should be included in all programs targeting vulnerable Romanians (such as street children, rural populations, and so on). Due to the extent of discrimination and the specific needs of poor Roma communities, specific programs addressing Roma should also be created. Roma should play a key role in program design, implementation, and monitoring.

Break-out Session 3 – Partnerships between Roma and civil society

The two break out groups discussing this issue took very different tacks. The first outlined the respective roles community organizations, international organizations, and government should play in advancing Romani health. The group decided that governments had the largest role to play; community and international organization roles should be limited to awareness raising. However, in the event that the government does not fulfill its role, community and international organizations should lobby for this. Major government responsibilities include improving health legislation and policy and funding these improvements. Priority areas for improvement include geographic coverage of primary care, community health facilities, the health insurance program, and the national medical ethics structure.

The second group identified integrated activities that governments and civil society could cooperatively undertake to improve Romani health. Several of these recommendations centered around the creation of new partnerships, such as the establishment of mixed working groups at the local, regional and national levels. At the same time, Romani individuals and NGOs should be more involved in governmental work. This should take the form of Romani employment in government, and Romani community involvement in policy and program development. Finally, both civil society and government must reach out to one another: the government should establish connections with grass-roots NGOs; the government should disseminate information in a clear and accessible manner; and NGOs should communicate better with the government.

Break-out Session 4 – Doctors and Mediators work towards Romani health empowerment

Both groups identified obstacles and required remedial actions. Obstacles were many; the most important included: physician and health authority perceptions that RHM's role

is to make physician and health authority jobs easier; doctors' prioritizing of their own needs; Romani community dependence on mediator presence; doctors pressuring mediators to do more than what is in their job description; doctors not wanting to do what they perceive as extra work; and, doctors not wanting to work with mediators at all.

Recommendations included actions that mediators, physicians, and the public health authorities should take. One was for greater information flow. Mediators should be able to inform and advocate vis-à-vis the health insurance system for greater coverage of Roma. Their job should not be to help Roma to survive within a poor health insurance system, but to improve the system. Indeed, mediators should have regular opportunities to give feedback to the public health system. Mediators would also benefit from sharing with each other; regular exchanges of experience between mediators in the same country and between mediators in different countries would help mediators to learn about patient empowerment. Greater physician involvement in RHM programs would ensure that physicians understand theirs and the mediators roles appropriately; a doctor should always work to educate and empower the patient. One team recommended that physicians who work with mediators should receive a professional reward. This might be continuing education.

Conclusions:

While conference participants came from a varying array of organizations, all agreed on a few key issues relating to Romani health and to RHM programs more specifically. These agreements were significant, as they may have been controversial just a few years ago. First, activist and governmental participants acknowledged that discrimination plays a key role in limiting Romani access to care, as well as the quality of care received. Second, multiple levels and types of approaches are required to address Romani health, and some of these approaches must be tailored to meet the specific needs of especially marginalized groups. Third, additional disaggregated data is required to better identify problems and solutions. This data must be collected by Roma themselves, and the Romani community must know what its function will be.

Participants also agreed on a few key overall principles, including Romani participation in policy-making, cooperation between governments and civil society, and an understanding of Romani health status that goes deeper than 'poverty.'

In terms of RHM programs, the Romanian RHMs in attendance pushed discussion toward identifying ways for RHMs to better achieve the stated goals of their roles. This will require greater financial and political commitment from all levels of government, as well as greater physician involvement. While cognizant of the need for RHM program improvement and for other types and levels of interventions, participants also agreed on the benefit of supporting and scaling up Romani health mediation. They were eager to learn about successful programs, and ways in which mediation can be funded, designed, and made sustainable.