

# Roma Health Workshop: Summary

June 21 and 22, 2004 - Budapest, Hungary

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## I. Overview and Objectives

The Roma Health Workshop was a joint initiative by the World Bank and the Open Society Institute, suggested during the first meeting of the International Steering Committee for the *Decade of Roma Inclusion* held in December 2003. During this meeting four broad areas of priority for the Decade were adopted: education, health, employment and housing, around which countries will adopt action plans identifying goals, relevant targets and suitable indicators to monitor progress. These plans should build on and improve countries' existing national strategies for Roma as well as incorporate innovative strategies that leverage on-going activities in the other sectors.

The Health Workshop was the third in a series of four meetings to assist countries in identifying and developing goals for each of the program areas<sup>1</sup>. Roma and non-Roma Government representatives and experts participated from Bulgaria, Croatia, the Czech Republic, Hungary, FYR Macedonia, Romania, Serbia and Montenegro, and Slovakia. The workshop *Agenda* and *Participant List* are attached to these minutes.

The purpose of the workshop was to assist countries in formalizing the health goals, targets and indicators for the Decade Action Plans. The Action Plans will be finalized in October 2004. The workshop provided a forum for country teams to critically examine current proposed plans and approaches in order to most effectively address a broad spectrum of social determinants of health.

This report provides an overview of the workshop and highlights key points. Each country gave a presentation of their proposed health goals, targets and indicators. These presentations along with presentations by the individual speakers are available on the website: [www.worldbank.org/roma](http://www.worldbank.org/roma)

## II. Introduction

*Ms. Kinga Göncz*, Minister without portfolio for Equal Opportunities, welcomed participants on behalf of the Government of Hungary. She spoke about the situation of Roma in Hungary and highlighted some measures already taken to improve access to health care by Roma, as well as their health status. She referred to the role played by housing conditions, lifestyle, education, employment and discrimination in their health status. The recent accession to the European Union ensures a special emphasis on minority populations and their inclusion across a number of social programs.

“In Hungary, the marginalization of Roma is reflected in a life expectancy that is around ten years shorter.”

*Kinga Göncz, Minister without portfolio for Equal Opportunities, Hungary*

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<sup>1</sup> The first meeting, on education was held in February 2004 and the second on employment in May 2004

*Mr. Julius Varallyay*, on behalf of the World Bank, gave a summary of the Decade of Roma Inclusion and its background. The Decade framework has permitted countries to make political commitments to design goals, objectives and indicators aimed at the integration of Roma in their country and reducing poverty of Roma. *Mr. Rob Kushen*, Director of International Operations at the Open Society Institute, highlighted the need to fight against the discrimination of Roma and to address the violation of human rights which impacts negatively on the health status of Roma. He also underscored the importance of Roma participation in the Decade process.

### **III. Key Recommendations for the Development of Health Action Plans**

- **Goals, Targets and Indicators** should be clearly defined. Goals should reflect the long-term vision and broad objectives of the country's strategy for improving Roma health. Targets should reflect the specific milestones necessary to achieve the goals. Indicators are the measures used to track progress and should focus on outcomes, not processes.
- Focus on **outcomes** not inputs when thinking about designing the Action Plans.
- Targets should be realistic and should be aimed at **reducing the gap** in the discrepancy between the majority population and Roma.
- Effective **data collection is essential** to the success of the Decade and critical to designing programming that is relevant and effective. National data collection systems need to be disaggregated by ethnicity and sex. Efficient data collection systems need to be institutionalized.
- Plans should have a concise timetable with specific milestones that can be linked to indicators over the ten year period.
- Integrate **cross-cutting themes** (gender, discrimination, and income poverty) into the Action Plans and into the strategic approaches to programs.
- An **inter-sectoral approach** is critical: work should be carried out across sectors, such as in education and housing. To varying extents, the four sectors selected by the Decade are overlapping and should be integrated, and the working groups from each of these sectors need to be informed on each Action Plan being proposed.
- **Roma involvement and participation** should be strengthened. Countries should adopt a collaborative approach and ensure there is a mechanism to involve Roma in finalizing the national action plans. Trust between different parties involved in establishing the Decade process is fundamental to its success.
- The **existence of legislation does not guarantee equal access to health care** – often the reality is different from the legal environment or legislation. Countries need to consider both the implementation of this legislation and other obstacles affecting access to health services for Roma.

### **IV. Main Points of Discussion of Country Presentations:**

- Goals, Targets and Indicators should be clearly defined and measurable. **Goals** are broad objectives linked to outcomes. **Targets** are specific measures which contribute to reaching the objectives. **Indicators** are the quantitative measures which can track progress. Although country teams should be realistic about what is achievable in ten

years, the Decade also provides an opportunity to be aggressive and build on current programs.

- The Millennium Development Goals (MDGs) provide a useful framework for conceptualizing the health action plans. More information is available at the website: <http://www.developmentgoals.org/>.
- Narrow the number of goals, targets and indicators based on health priorities and focused on health outcomes. It is better to aim for fewer, quality oriented goals which will have a real impact than to have a long list of less specific goals.
- Use proportional measures and not absolute numbers for data collection indicators.
- Integrate gender into the design, monitoring and implementation of programs (i.e., consider the special needs of girls/women; ensure that indicators are disaggregated by gender).
- Consider all social determinants of health in your analysis – including infrastructure and environment. Prioritize and then choose goals/targets/indicators that are realistic but will have the most impact on the health of Roma individuals.
- Consider not just the existence of legislation (i.e. universal access to health insurance) but whether or not the legislation is actually getting the job done. For example, are there are obstacles to Roma accessing insurance even if the legislation is on the books.
- The discrimination of Roma in accessing health care and sanitation services must be addressed. Some countries have proposed an ombudsman system for monitoring any refusal of the right to health.
- Include a time-frame for scaling up over the ten years.
- Explore health care financing plans that take into consideration the special needs of vulnerable populations.
- Work inter-sectorally to determine what other sectors might be usefully engaged.
- Ensure cooperation and involvement of national and local governments.

## **V. Health Determinants**

*Ms. Karen Plafker* from OSI's Network Public Health Program and *Dr. Nedim Jaganjac* from the World Bank gave a presentation on effective policies to address the determinants of health. Improving the health of vulnerable or marginalized populations requires a comprehensive, inter-sectoral approach. Health planners must not only consider the obvious provisions of health care but must analyze the obstacles that prevent individuals and communities from reaching good health and then design innovative, effective responses.

“Health is a precondition for wellbeing and the quality of life. It is a benchmark for measuring progress towards the reduction of poverty, the promotion of social cohesion and the elimination of discrimination.”  
*World Health Organization, Euro's Health 21*

Tremendous changes throughout the region since the break-up of the Soviet Union have resulted in serious equity problems. Countries have a moral and economic imperative to address these inequalities now by considering issues of decentralization, separation of purchasing and provision, and the development of an effective primary health care system.

Key considerations include:

- Understanding the difference between availability and access; equity and equality,
- Quality of care must include treatment that is non-discriminatory.
- Cross collaboration between the other Decade sectors is key.

Four concrete recommendations for Decade Action Plans include:

- Ensure Roma participation in the Decade process, from planning through implementation through monitoring
- Think about outcome goals. Look at the MDGs as an example of long term goals, targets and indicators.
- Ask “why” five times. Is the range of health determinants addressed by your Plan?
- Review Action Plans from other sectors. What do they say about health? And what *should* they say about health?

## **VI. Break-out Group: Delivery of Services**

*Dr. Urmos Andor* with the Government of Hungary’s Roma Integration Directorate led a discussion on delivery of services giving an overview of the socio-economic and health situation of Roma in the region. In particular, the gap between Roma and the majority population in morbidity, education, employment and infrastructure was highlighted. This was contrasted with statistics on access to family services by region and contrasted with the local underprivileged populations. He mentioned discrimination as a fundamental problem when considering questions of health care for the Roma.

*Mr. Keith Conn* from Health Canada gave a presentation on Health Canada’s efforts to address the gap in health status between First Nations and Inuit populations and the general Canadian population. Health Canada’s objectives stress ensuring availability of, or access to, quality health services and supporting greater control of the health system by First Nation and Inuit communities. Mr. Conn described how the experience from Canada is analogous to the Roma situation in Eastern/Central Europe in that the health system must ensure services to a marginalized and dispersed population that suffers a high burden of illness, poor socio-economic conditions and uneven local level organizational and management capacity.

### **Major Recommendations:**

- Governments should show strong, high level commitment and willingness to work in partnership with communities and civil society groups.
- Enhanced funding is needed from governments to address gaps in health status in most marginalized communities.
- The real needs of Roma communities should be identified through an effective assessment mechanism.
- Special attention has to be paid to the needs of Roma women.

- The data collection and analysis issue needs to be established and integrated into national systems.
- Clear indicators and targets should be established.
- Cooperation between public administration institutions and the active involvement of local level institutions is required.
- Equity in education, health and access to institutions is fundamental.
- Establishing indicators should take baseline data into consideration.
- The effect of the socio-economic status of Roma communities on the health status of its members is an important consideration.

## **VII. Break-out Group: Enabling Health, including access to services**

*Mr. Ivan Ivanov* of the European Roma Rights Centre (ERRC) gave an overview of the barriers Roma face across the region in accessing health care. Wide-spread discrimination against Roma is a major obstacle to improving health in Roma communities and effective methods to combat this discrimination must be instituted.

*Ms. Patricia Bezunartea* of the Fundacion Secretariado General Gitano (FSGG) gave a presentation of their experience in trying to address health needs of Roma and drew lessons learned on best practices to create an enabling environment for improving access to health services for vulnerable populations. FSGG's experience in Spain indicates that the first step to improving Roma health (or the health of any vulnerable population) is ensuring free access to health services. Under the current system in Spain, universal health care services for all Spanish citizens, regular immigrants and non regular immigrants (for emergency services) is provided and does not depend on work status. Additionally, health policy has been decentralized as well as the financing for direct services.

### Major Recommendations:

- Combating discrimination in access to health services needs to be an integral part of the national Roma health strategies.
- Services should be mainstreamed, comprehensive and strategies long-term.
- Investments should be made in building the capacity of the Roma population.
- Networking is crucial.
- Maintain a gender perspective in the development and implementation of all programs.
- Document and disseminate best practices and then invest in scaling up pilot programs.
- An independent investigative body should be established within the government in order to investigate reports of discrimination.
- Informational and educational programs for the community and medical staff should be provided.
- In service training for health care workers established in order to sensitize them to special needs of vulnerable populations.

- Information about requirements for obtaining health insurance must be provided by effective outreach programs.
- Governments need to consider a more equitable distribution of resources for health based on the needs of the population.
- Explore incentive systems to encourage medical staff to work with Roma.
- Initiate affirmative action programs to integrate Roma as health care providers into the larger community (doctors, nurses, medical aids, etc.).
- Include and promote Roma representatives at the ministry of health level and at other national institutions.
- Implement programs for the early diagnosis of TB, hepatitis, and other infectious diseases

### **VIII. Data Needs and Monitoring**

Data are essential for the success of the Decade. Each country will identify data needs and select reliable and available indicators that can be used to monitor progress on employment and the Decade goals. UNDP is coordinating work on data for the Decade, including the expert's working group and launching a baseline survey that will aim to cover all of the countries in selected areas. The Expert's Group on data collection informs and supports country groups on methodologies for sustainable data collection on vulnerable groups, coordinates the base-line surveys, elaborates possible approaches to overcome legal barriers and prepares guidelines for training of Roma activists to participate in data collection and analysis. The group includes one member from the Statistical office, one member from the respective "Minority issues" councils and participation from the Roma civil society.

Systems for data collection for the Decade should be designed taking into consideration existing data collection systems and integration into national census plans. Data are needed both to assess progress in reaching the Decade goals and for evaluating the impact of programs and policies on Roma outcomes. This will require both an analysis of existing national legislation to address issues of disaggregating data by ethnicity and outreach to Roma communities. Outreach is required both to ensure inclusion and to raise awareness on the importance of declaring ethnicity in surveys.

Some issues specific to data collection and Roma are listed below.

- Involve national statistics offices in the design of data systems for The Decade. The Working Group on data coordinated by UNDP provides an ideal venue. The baseline survey can be an important source of information, but should not be considered a substitute for each countries' own efforts to upgrade existing statistical instruments to cover Roma.
- Use broad definitions for defining Roma populations. If someone is considered to be Roma by the majority population, they should be treated as Roma in the analysis as exclusion is based upon majority views.
- For sampling design identify Roma households and sample from them. Samples cannot be based only on census data, but need to be complemented by expert/Roma NGOs estimates. To protect privacy, lists of Roma should be destroyed after they are

used. Larger sample sizes are important in order to make sure that the survey is representative.

- In order to have reliable and rigorous results, the actual achievement of the program needs to be compared with the counterfactual. In other words -- what would have happened in the absence of the program? This presents a challenge, as counterfactuals are difficult to identify. There are also ethical questions – should some groups or communities be excluded from a program for analytical purposes? The most realistic approach is to identify “natural experiments” and to search for control groups which exist in the absence of the program. Even if policies do not target Roma, their specific impact on Roma should be assessed.
- Evaluations need to be clear about the objective of the programs, in order to monitor and evaluate the right outcomes.
- Involve Roma researchers and NGOs in the preparation, implementation and analysis of surveys to ensure quality and Roma ownership of the process. This will increase quality and acceptance of the results.
- Take into account differences in Roma communities when designing and analyzing the surveys.

## **IX. Health Financing**

*Ms. Nata Menabde* of the World Health Organization gave a presentation on health system goals in addressing the barriers to the use of health services. WHO is involved in a wide variety of issues related to poverty – including extreme poverty as a cause of death. Three main goals of health systems include:

- Improving population health;
- Improving equity in health – minimizing avoidable or unfair difference in health between individuals and social groups;
- Improving protection against financial risk (i.e., the need for health care should not impoverish individuals).

“The world’s biggest killer and the greatest cause of ill health and suffering across the globe is listed almost at the end of the International Classification of Diseases. It is given the code Z59.5-extreme poverty.”  
***World Health Report 1995: The State of World Health – WHO, Geneva***

There is a strong link between equitable financing and the overall health of the population. Some considerations to address issues of appropriate health financing include:

- Broad-based risk pooling is an important health policy objective – especially for vulnerable populations.
- It is essential to collaborate and mobilize all the resources in order to improve Roma health.
- The transition countries have an opportunity to explore payment exemptions for vulnerable populations due to existing capacity in terms of documentation and information systems.

**Mr. Imre Hollo** gave an overview of the Hungarian experience in trying to address inequalities in health care financing. In particular, the presentation explored the relationship between health needs and funding. Observations included:

- There are significant regional differences in health outcome and input indicators.  
BUT:
- The varying allocation of health care resources cannot be explained by health needs, social status, and perception of good health or age structure.
- Inequalities in health indicators are better explained by social and economic indicators.
- More complex and targeted interventions are necessary to address these disparities.