How the Global Fund Can Improve Roma Health

An assessment of HIV and TB programs in Bulgaria, Macedonia, Romania, and Serbia

OPEN SOCIETY INSTITUTE
Public Health Program

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Abbreviations

CCM	Country Coordinating Mechanism
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV/AIDS	Human Immune Deficiency Virus/Acquired Immune Deficiency Syndrome
IDP	Internally Displaced Person
IDU	Injecting Drug User
IEC	Information, Education, and Communication
MSM	Men Who Have Sex with Men
NGO	Nongovernmental Organization
PLWHA	People Living With HIV/AIDS
PMU	Program/Project Management Unit
PR	Principal Recipient
STI	Sexually Transmitted Infections
VCT	Voluntary Counseling and Testing

Executive Summary

This report assesses the impact of projects sponsored by the Global Fund to Fight AIDS, Tuberculosis and Malaria ("the Global Fund" and "GFATM") in Roma communities in **Bulgaria**, **Macedonia**, **Romania**, and **Serbia** and discusses the challenge of delivering HIV/AIDS and TB services to particularly vulnerable groups. The report also examines the involvement of Roma civil society in the development of proposals and implementation of projects sponsored by the Global Fund.

Roma communities are by far the most disadvantaged in Europe. This is reflected in their health status and access to health care. The available information indicates vast discrepancies between the health of members of Roma communities and the health of members of majority populations and other ethnic groups. Poverty, often extreme, inadequate housing, lack of identity papers, inadequate access to health care, and lack of education and unemployment are all factors that influence health; a vast majority of Roma in Central and Eastern Europe face these problems.

The limited data available show that groups within Roma communities in **Bulgaria**, **Macedonia**, **Romania**, and **Serbia** may be especially vulnerable to HIV/AIDS and TB. Sex work and drug use often accompany conditions of poverty and deprivation, which increase the risk of HIV infection for particularly vulnerable groups, including women, street children, and drug users. Poorer people are also more susceptible to TB, largely due to the conditions in which they live. Yet, state policies dealing with health and Roma have so far taken insufficient account of the vulnerability of members of Roma communities to HIV/AIDS and TB.

The unique architecture of the Global Fund puts it ahead of other donors when it comes to the ability to be responsive to the experience and expertise of a wide spectrum of stakeholders, including civil society. The Global Fund provides countries an opportunity to respond rapidly and flexibly to counter the negative impacts of the HIV/AIDS and TB epidemics. The Global Fund has provided substantial funding to fight HIV/AIDS and TB in the four target countries. However, the results of the present assessment show that, with few exceptions, relevant national governance structures do not always have sufficient representation of civil society, and particularly of Roma. This assessment suggests this is due to two key factors: the lack of transparency and accessibility of in-country GFATM processes to Roma organizations, and the sometimes limited capacity of Roma organizations to be involved or take a more active role.

The Roma components of GFATM grants have been positive, because, with few exceptions, national Roma policies do not address HIV/AIDS and TB, or sometimes even health, as priorities. However, the underlying causes of vulnerability of Roma groups to

HIV/AIDS and TB have not been sufficiently addressed in GFATM projects. The approach furthermore has been to target the Roma community as a whole rather than targeting groups at risk within Roma communities, as is the case for the majority population. Such a focus obviously requires research on the at-risk groups in Roma communities, given the scarcity of disaggregated health data on Roma populations, and better elaboration of the target groups. However, research and even careful needs assessments within Roma communities, with few exceptions, have not been done. GFATM projects also tend to lack coordination with other related initiatives on Roma health, which deprives the projects of valuable experience and expertise, and ultimately limits their impact.

Lastly, the long-term sustainability of the GFATM projects remains in question. This is a particular concern to stakeholders in **Serbia** and **Macedonia** where grants have ended or are close to ending. In **Bulgaria** and **Romania,** which are no longer eligible for new GFATM grants due to increases in gross national income, alternative sources of funding, such as from the European Regional Development Fund, may be needed to fill future gaps.

Recommendations

Involving Roma civil society in Global Fund processes and projects

To the Global Fund Secretariat:

- Encourage Country Coordinating Mechanisms (CCM) and principal recipients (PR) to include Roma in the development and implementation of GFATM projects;
- Invite Roma representatives to appropriate GFATM meetings, such as regional meetings and the Partnership Forum, and meet with Roma stakeholders during country visits;
- Disseminate more user-friendly information about Global Fund processes, procedures, and requirements to facilitate access by civil society generally, including Roma civil society, to this knowledge.

To Country Coordinating Mechanisms:

- Create opportunities to involve appropriate Roma stakeholders from diverse communities in the work of the CCM, including proposal development and project design, and monitoring and evaluation. Where it has not been done, create space for, and develop, transparent national guidelines for the election of Roma NGOs/stakeholder representatives on the CCM;
- Publish information on GFATM funding opportunities in minority languages, to encourage applications from a wider range of civil society organizations and stakeholders;
- Include a budget for institutional capacity building in each grant proposal so Roma and other NGOs can improve their capacity to implement HIV/AIDS and TB projects.

To Principal Recipients:

- Involve Roma stakeholders from diverse communities in the management, monitoring, and evaluation of GFATM projects;

- Introduce application criteria for subrecipients and sub-subrecipients that encourage the involvement of Roma stakeholders as partners in implementing GFATM projects;
- Provide support for training to build the capacity of Roma NGOs that are currently serving as informal project partners in the implementation of GFATM projects, to enable their future participation as official partners;
- Support the development of Roma NGOs and networks to increase their capacity to address health issues.

To civil society:

- Promote intercultural dialogue with Roma organizations on sensitive topics, such as sex, HIV/AIDS, TB, and other diseases;
- Help keep Roma civil society informed of opportunities for involvement in the development and implementation of the GFATM and other donor-funded projects;
- Explore possibilities of forming coalitions with Roma NGOs to increase the reach of GFATM projects and strengthen GFATM proposals.

To Roma NGOs:

- Actively seek to be involved in GFATM processes at the country level, advocate for the inclusion of programs focused on groups at risk within Roma communities, and raise awareness of the barriers or challenges in doing so. Submit proposal applications not only for Roma-specific but also for non-Roma components of the GFATM grants;
- Monitor the effectiveness of Global Fund programs that focus on meeting the needs of groups at risk within Roma communities;
- Strengthen institutional capacity in the areas of administrative and financial systems and program management, in order to increase capacity to implement HIV/AIDS and TB projects.

To other donors:

- Continue to provide funding to Roma and other NGOs for HIV/AIDS and TB projects to help them ensure the sustainability of their work, build capacity, and maintain their autonomy.

Improving Global Fund impact on Roma health

To the Global Fund Secretariat:

- Encourage the harmonization of GFATM grants with other donors and initiatives tackling Roma poverty and exclusion as an underlying cause of poor health status, such as the National Action Plans for the Decade of Roma Inclusion and European Union initiatives.

To Country Coordinating Mechanisms:

- Conduct thorough needs assessments on TB and HIV within Roma communities in order to inform the development of GFATM proposals and include operational research in GAFTM proposals to better assess the needs of various subgroups within Roma communities who may be at an elevated risk of HIV/AIDS and TB;
- Articulate specific at-risk groups within Roma communities in GFATM proposals, such as injecting drug users (IDUs) and sex workers, rather than targeting the whole community on the basis of ethnicity;
- Include reliable estimates in GFATM proposals of Roma populations, including undocumented individuals, alongside official data;
- Coordinate funding and projects with other relevant national and international Roma health policy frameworks, most notably the National Action Plans for the Decade of Roma Inclusion;
- Put measures in place to ensure the long-term sustainability of project interventions, such as requiring municipalities to provide matching funds for HIV and TB projects in official budgets.

To Principal Recipients:

- Coordinate project interventions for target groups within GFATM proposals, such as IDUs, sex workers, and men who have sex with men (MSM), with interventions for groups at risk within Roma communities.

To national health planners:

- Step up the implementation of Roma poverty-reduction and inclusion measures, most notably the National Action Plans for the Decade of Roma Inclusion, and ensure that GFATM projects are coordinated with these initiatives;

- Support research and needs assessments on TB and HIV among the most at-risk groups within Roma communities;
- Facilitate access to nonemergency medical services, particularly HIV and TB testing and treatment, for persons without personal documentation or registration.

To other donors:

- Harmonize funding for Roma poverty reduction, inclusion, and health initiatives with GFATM projects;
- Invite GFATM representatives, principal recipients and major subrecipients to participate in the Roma Decade meetings and events.

To civil society:

- Ensure that the most at-risk groups among Roma communities are specifically targeted through outreach activities and reached by HIV and TB services.

To Roma NGOs:

- Advocate harmonizing the GFATM funding and projects with relevant Roma-related policies and initiatives;
- Encourage most at-risk members of Roma communities to take advantage of available HIV and TB services.

Introduction

In 2006, the HIV/AIDS pandemic in Eastern and Central Europe was one of the fastest growing worldwide. In 2007, the tuberculosis epidemic gained recognition as a regional emergency, and international monitors are calling on national governments to step up their responses and effectively engage civil society. Although the HIV/AIDS and TB epidemics can affect everyone, members of vulnerable communities are usually among the most affected and least protected. Roma communities in Eastern and Central Europe have long suffered from poorer health than the majority populations by almost every indicator, and the Roma of these regions are undoubtedly among the most vulnerable to HIV/AIDS and TB.

The Global Fund to Fight AIDS, Tuberculosis and Malaria (hereafter "the Global Fund" and "GFATM") was created in 2002 as an innovative financing mechanism that seeks to rapidly raise and disburse funding for programs that reduce the impact of HIV/AIDS, tuberculosis, and malaria in low- and middle-income countries. Unlike other donors, the Global Fund provides aid to country governments and country stakeholders based on proposals designed by multisectoral processes conducted in the countries themselves. Moreover, support for civil society involvement is one of the Global Fund's fundamental principles. The Global Fund has quickly become one of the most significant aid mechanisms, providing 20 percent of global funding for HIV/AIDS, and 66 percent for tuberculosis and malaria in 2006.

The goal of this report is twofold. The first goal is to examine both the role of Roma civil society in GFATM processes as well as the engagement of Roma civil society in the implementation of grants in Bulgaria, Macedonia, Romania, and Serbia. The second goal is to assess how effective the Global Fund has been at reducing the risk of HIV/AIDS and TB in target Roma communities in these four countries. The report concludes that the HIV/AIDS and TB activities funded by the Global Fund are increasing access to HIV and TB services for Roma communities in most countries; however the issues that place certain vulnerable groups among Roma at a higher risk of HIV/AIDS and TB infection are still not being addressed. Further, GFATM-funded projects within Roma communities are often not based on a solid assessment of needs and are not coordinated with other Roma health initiatives, limiting their overall impact. The report's recommendations provide concrete steps for better addressing Roma health concerns and engaging Roma nongovernmental organizations (NGOs) in proposal development and project implementation.

The Global Fund has approved grants in all four target countries in the areas of HIV/AIDS and/or TB. Some of the components of these grants have specifically targeted Roma communities. However, there has not been an assessment of how much of this money

has actually reached Roma communities and to what extent Roma civil society has been involved in designing or implementing GFATM grants.

Assessment Methodology and Report Structure

The report is based on desktop and field research by national researchers in Bulgaria, Macedonia, Romania, and Serbia.

In the course of the fieldwork, interviews were conducted with major stakeholders from the Roma community, such as NGO leaders and civil society representatives. Various subgroups within the Roma community, such as street children, sex workers, refugees and internally displaced persons (IDPs), persons with unregulated legal status, homeless, and drug users, were also interviewed, both individually and in focus groups, with the use of specifically designed interview guides. Other stakeholders interviewed included members of Country Coordinating Mechanisms (CCMs), representatives of principal recipients (PRs) of GFATM grants, national health decision makers, and various NGOs representatives engaged in GFATM projects, as well as representatives of NGOs not receiving GFATM funding.

Preliminary findings of the Global Fund and Roma assessment were presented at a meeting convened by the Open Society Institute (OSI) in late January 2007, in Malaga, Spain, to solicit participants´ feedback and critiques. The meeting was attended by representatives of OSI´s Public Health Program, Soros foundations, and members of the assessment team, and resulted in refining the assessment methodology and shaping the general structure of the report and recommendations.

The structure of the report is as follows: an executive summary of the research findings with general recommendations for the Global Fund Secretariat, CCMs, PRs, national health planners, other donors, and civil society on: 1) the involvement of Roma civil society, and 2) the impact on Roma health. The body of the report consists of a background section reviewing the status of Roma health and relevant state policies in the four countries, and two parts that assess Roma involvement in GFATM proposal development, governance and grant implementation and the impact of GFATM funding on Roma health. The national reports, available separately,[1] focus in more detail on the situation in the individual target countries and make specific recommendations on the basis of country findings.

Background: Roma Health and HIV/AIDS and TB

General Health Indicators

Roma communities[2] are by far the most disadvantaged in Europe. This is reflected in health status and access to health care. Despite a lack of reliable disaggregated data not only regarding the health condition of Roma but often even their numbers, the available information indicates vast discrepancies between the health status of Roma communities and that of majority populations or other ethnic groups. Poverty, often extreme, unsanitary housing, lack of identity papers, inadequate access to health care, and lack of education and unemployment are all determinants of health. The vast majority of Roma in Central and Eastern Europe face these problems.

In recent years, the health status of Roma in **Bulgaria** has significantly deteriorated, and state health care reform has inadvertently contributed to this deterioration. State health policy, now based on a social health insurance system, practically excludes socially vulnerable groups, among whom Roma are overrepresented. As a result of amendments to the health insurance act, about one million Bulgarian citizens (approximately 13 percent of the population) are currently excluded from the state health insurance system;[3] 55 percent of Roma indicate that they have only limited access to health care services, and 46 percent do not have health insurance and are deprived of access to any health care services.[4]

A complex set of circumstances, including lack of education, poor living conditions, and lack of documentation—especially among numerous internally displaced persons and refugees—are reflected in the overall poor health status of the Roma population in **Macedonia**.[5] Many Roma are not eligible for state health care because they lack Macedonian citizenship, because they are not officially employed and thus do not qualify for medical insurance, or because of other subjective or arbitrary reasons, such as discriminatory attitudes of health workers.[6, 7]

Various studies[8] emphasize the poor living standards of **Romania's** Roma population, including inappropriate housing conditions, which are an important determinant of health. Roma access to medical services is also impeded for various reasons. Lack of identity papers, which are required for accessing public health services, leaves an estimated 11 percent of undocumented Roma with access to emergency medical attention only.[9] Prejudice and discriminatory attitudes of some medical staff toward Roma, reflecting attitudes prevalent in society as a whole, also present a significant barrier. However, there is no mechanism

for combating discrimination in the field of health care in practice, despite the fact that laws and regulations on the books prohibit it.

In **Serbia**, limited data collected for the Roma population show that the health status of Roma is far worse than the health status of the general population.[10] The causes of this situation are closely related to poverty and exclusion: the unemployment rate among Roma is four times higher than average in Serbia; 32.5 percent of Roma are without education or have less than four years of schooling.[11] Furthermore, poor living conditions and discrimination in accessing health care services have an additional negative impact on Roma health.

Vulnerability to HIV/AIDS and TB

There are no official statistics or research findings in any of the target countries about drug use or sex work—among the principal risk factors associated with HIV transmission in the region—for different Roma communities. Sex and sexuality are considered taboo topics within Roma communities, and discussion of drugs, drug use, and incarceration is usually avoided by Roma leaders and civil society organizations due to the social stigma attached to these issues. However, Roma sex workers, drug users, and prisoners may be more vulnerable to HIV/AIDS and TB than sex workers, drug users, and prisoners from the majority populations in these countries, and state policies dealing with health and Roma have so far taken insufficient account of the vulnerability of members of Roma communities to HIV/AIDS and TB.

Even the limited available data show that isolated Roma neighborhoods may be especially vulnerable to HIV/AIDS and TB. Most Roma in the target countries live in conditions that contribute to their poor health status. Sex work as well as drug use often accompany conditions of poverty and deprivation, which increases risk of HIV infection for particularly vulnerable categories of people, including women, street children, and drug users. Poorer people are also more susceptible to TB.[12]

Surveys on the behavior of IDUs in **Bulgaria** indicate that Roma engage more frequently than members of the general population in practices such as frequent injecting and needle sharing, which puts them at risk of HIV infection.[13] Registration rolls of needle exchange programs show that Roma clients in some cities account for 40 percent of the total number of clients.[14] Roma are also disproportionately affected by tuberculosis, which is on the rise in Bulgaria. In some areas, Roma make up 60 percent of tuberculosis patients.[15]

Health statistics in **Macedonia** are not disaggregated by ethnicity, and as a result data on Roma is limited. Undocumented Roma individuals, many of whom live in informal settlements with particularly precarious living conditions, and who account for at least two-thirds of the Roma population, are most at risk of TB infection. However, most of the

programs and projects directed at Macedonia's Roma, including those supported by the Global Fund, do not take into account the undocumented population.[16]

In **Romania**, knowledge of contraception is relatively low among Roma compared with the overall population. Fewer than 50 percent of Roma respondents in one survey knew of at least one method of contraception, compared with over 99 percent of the total number of respondents.[17] Only about 25 percent of Roma respondents declared they used one of the known methods of contraception at least once, compared to 48.2 percent of the women and 51.3 percent of the men overall.[18] This suggests that certain groups from Roma communities at risk for sexual transmission of HIV, such as sex workers and MSM, may run a higher risk of HIV-infection than at-risk groups from the population overall.

There is no specific official information in **Serbia** about the incidence of HIV/AIDS and TB infection among Roma. Yet the conditions of deprivation faced by the country's Roma population suggest a heightened risk of TB and HIV infection among particularly vulnerable groups, including refugees living in slums, homeless people, street children, sex workers, and drug users. Paradoxically, this has been acknowledged by the inclusion of these target groups in GFATM projects.

State Policies

Despite evidence of poor health outcomes in Roma communities, national health policies do not always address the specific health needs of Roma. At the same time, policy documents that do focus specifically on Roma health often ignore HIV/AIDS and TB.

In **Bulgaria**, few health policy documents mention Roma, while Roma-specific documents fail to recognize and include HIV/AIDS prevention as a strategic objective. *The National Program for Prevention and Control of AIDS and Sexually Transmitted Diseases 2001–2007* does define Roma as one of the risk groups that need special interventions for prevention of the transmission of HIV due to their overall social isolation and disadvantaged social and health situation. However, it does not identify specific at-risk groups within the Roma community. *The National Program for Prevention and Control of Tuberculosis in the Republic of Bulgaria 2007–2011* (in progress) mentions Roma, in contrast to its predecessor program. *The National Program for Prevention, Control and Rehabilitation of Drug Addictions in the Republic of Bulgaria 2000–2005* does not mention Roma or the need for specific harm reduction interventions for minorities.

In **Macedonia**, the latest *HIV/AIDS National Strategy 2007–2011* was under preparation when research for this report was conducted, but according to Ministry of Health officials, Roma are not a target group.[19] Sources at the Ministry of Health told researchers that the new *TB Strategy 2006–2010*—also under preparation at the time when this report

was researched—does not consider Roma to be an at-risk group, either.[20] HIV/AIDS and TB are not a focus of the Roma-oriented policy documents prepared for the Roma Decade.

In **Romania**, the *National Strategy for Surveillance, Control and Prevention of HIV/AIDS Cases 2004–2007* does not explicitly mention Roma. The major document concerning Roma, the *2001 Strategy of the Government of Romania for the Improvement of the Roma Situation*, does not mention TB or HIV/AIDS. Only in the *Roma Decade National Action Plan on Health* are TB, HIV/AIDS and sexually transmitted infections (STIs) mentioned specifically as focus areas.

In **Serbia**, the *National Strategy for the Fight against HIV/AIDS* targets Roma among vulnerable groups estimated to encompass 59 percent of the total population. The *Program for TB Control* mentions Roma living in slums as one target group. However, the *Draft Strategy for Integration of Roma and the Roma Decade National Action Plan on Health* do not mention TB or HIV/AIDS explicitly.

Roma populations in the four target countries live overwhelmingly in conditions of poverty and exclusion, which have a negative impact on their overall health status. Poverty and deprivation, compounded by barriers in accessing health care, are also factors increasing the vulnerability of certain groups among Roma to HIV/AIDS and TB, something that needs to be carefully considered when devising appropriate health interventions. State policies so far have not paid sufficient attention to the vulnerability of specific members of Roma communities to HIV/AIDS and TB.

The Global Fund and Roma Civil Society Involvement

The Global Fund provides countries an opportunity to respond rapidly and flexibly to counter the negative impacts of HIV/AIDS and TB. The Global Fund has provided substantial funding to fight HIV/AIDS and TB in the four target countries. However, the results of this assessment show that, with few exceptions, the relevant national governance structures do not always have sufficient representation of civil society, and particularly of Roma. Our assessment suggests this is due to two key factors: the lack of transparency and accessibility of in-country GFATM processes to Roma organizations and the sometimes limited capacity of Roma organizations to be involved or take a more active role.

Global Fund Architecture

The Global Fund has a unique management architecture. Even though it does not have a direct presence in the recipient countries, it has created a system of grant administration and oversight in each recipient country, which includes the CCM, PRs, and local fund agents (usually large accounting firms).

The CCM is a country-level body that prepares funding proposals and oversees grant implementation. In accordance with the GFATM guidelines,[21] CCMs must be composed of a diverse and representative membership of in-country stakeholders, including representatives from governments, multilateral and bilateral donors, NGOs, academic institutions, private-sector representatives, and people living with or affected by HIV/AIDS, TB or malaria. Each sector's representatives must be selected through a transparent and inclusive process by their respective sector.

PRs are designated in-country organizations chosen by the CCM to receive funding allocations, implement programs, and distribute funds to subrecipients according to the grant agreement. The PRs are legally responsible for the funds and implementation. Often, the PR is the Ministry of Health or another governmental body (about 65 percent of grant projects). In some countries, civil society organizations (20 percent of grant projects), or international institutions, such as the United Nations Development Program (another 15 percent of grant projects), act as PRs.[22]

The Global Fund contracts local fund agents in countries where grants have been awarded to independently oversee, verify, and report on grant progress. Local fund agents are not a focus of this report.

The Global Fund solicits proposals through funding "rounds." There is usually one funding round per year, depending on available resources.

Type and Level of Funding in Target Countries

The Global Fund plays a leading role in fighting HIV/AIDS and TB among Roma communities in the four target countries by providing resources where most other donors and programs either do not focus on Roma health specifically, or do not focus on TB and especially HIV/AIDS among groups at risk within Roma communities.

The Global Fund grants to the four countries have been as follows (Table A).[23]

Table A: Global Fund Grants to Bulgaria, Macedonia, Romania, and Serbia

	GFATM Grants	Roma component
Bulgaria	HIV/AIDS (Round 2): $15,711,882	U.S. $1.37 million was budgeted for Roma-specific interventions. Ten Roma NGOs are subrecipients in 10 cities for HIV/AIDS activities.
	TB (Round 6): $20,928,706	Roma NGOs and community members will be engaged in providing TB prevention and treatment services in 28 localities.
Macedonia	HIV/AIDS (Round 2): $5,904,367	Seven Roma NGOs are sub-subrecipients for HIV/AIDS activities.
	TB (Round 5): $3,071,097	Although the TB grant includes interventions in Roma communities, no Roma NGOs are subrecipients of GFATM funding.
Romania	HIV/AIDS (Round 2): $26,861,313	No Roma NGOs are involved in grant implementation for either the Round 2 or Round 6 HIV/AIDS grants, although both include Roma components.
	HIV/AIDS (Round 6): $12,092,735	
	TB (Round 2): $16,743,641	One Roma NGO is a subrecipient for TB activities in Round 2 and 6.
	TB (Round 6): $10,834,509	
Serbia	HIV/AIDS (Round 6): $12,915,457	For the Round 6 HIV/AIDS grant, $135,000 per year has been allocated for activities among groups at risk within Roma communities.
	TB (Round 3): $4,087,979	Red Cross Serbia, a subrecipient for the TB grant, has identified and worked with key informants among Roma communities.

These levels of funding put the Global Fund ahead of all other donors in the region for HIV/AIDS and TB. Inadvertently, this has also prompted some donors to discontinue or redirect funding, in order to avoid overlap, with negative consequences for NGOs who relied upon their funding. For example, in **Bulgaria**, various stakeholders interviewed for this report said that the GFATM project on HIV/AIDS brought significant benefits to many small NGOs that operate with GFATM funds only, but had a negative impact upon NGOs with greater capacity and good international experience and image. This impact occurred because some international donors ceased their support to Bulgaria once the GFATM grants entered the country and left some NGOs entirely dependent on the GFATM funding through the Ministry of Health, the principal recipient of the GFATM funds. This approach creates a risk that NGOs will lose their independence from governments and compromise their role as watchdogs and advocates.

Country Level Governance and Project Implementation

Despite the Global Fund's requirements for broad stakeholder participation, the governance structures in the target countries, with few exceptions, do not always include sufficient representation from civil society, particularly Roma civil society.

In **Bulgaria**, the Global Fund's country governance consists of the CCM and the PR, which has created a Project Management Unit (PMU) to manage the grant. The PMU is comprised of a team of long- and short-term consultants, which, in effect, has direct control over all aspects of the project. The CCM includes one representative of the Roma community/NGOs (although only since August 2006), who was freely and transparently elected by NGOs. Field research has shown, however, that awareness among Roma civil society about what the CCM is and what it does is quite limited.[24]

The PR in Bulgaria is the Ministry of Health, which was selected by the CCM because it was the lead actor in the preparation of the project. The PMU at the Ministry is responsible for the operational administration and is led by a project director. Each component (HIV/AIDS and TB) has a long-term consultant responsible for its overall design and direct control. The long-term consultant engages a team of short-term consultants who carry out trainings, local consultations, and monitoring and evaluation of the activities carried out by sub-recipients. Consultants are hired through personal contracts with the Ministry of Health on the basis of their professional background and proven expertise.[25] This team has included, at different stages, Roma experts who were based in Sofia and selected on the basis of their professional experience.

The subrecipients (who are the main project implementers) are NGOs, some state organizations, and municipalities. Roma are quite well represented at the implementation stage—unlike in other countries discussed in this report. However, they still do not have much flexibility or room for initiative when it comes to project implementation. The project management is top-to-bottom and impeded by heavy bureaucratic procedures. In the first years of the project, the PMU managed all aspects of the operation of the subrecipients, including the project staff selection within the NGOs. This strong centralization and control even led to the requirement that subrecipients not implement or take part in any other projects.[26] Later in the project, the NGOs were allowed more autonomy. Still, NGOs claim their views are usually not taken into account in project planning.

In **Macedonia**, the CCM's 47 members include representatives of ministries, multilateral agencies, academic institutions, the private sector and professional organizations, religious groups, NGOs, and people living with HIV/AIDS (PLWHA) and/or TB. The appointment of the original CCM members from the NGO sector was based on their participation in the preparation of the Round 3 proposal. Since then, some members of the CCM have changed as a result of political developments in the country. However, neither the previous, nor the current CCM has had designated representation from the Roma community. At the time of the preparation of this report, the CCM was undergoing reforms. It is unknown if Roma representation has been improved in the new CCM.

The PR in Macedonia is the Ministry of Health. In addition to the PR, several subrecipients are preselected by the CCM. In Round 3, NGOs that actively participated in the proposal preparation process became subrecipients; thus, they were pre-selected by the CCM to participate in the implementation of the grant. Seven Roma NGOs have participated in implementing this grant as sub-subrecipients. Initially, the PR deemed them to lack capacity to be involved at the subrecipient level, and proposed to build their capacity to become subrecipients later in the grant cycle. However, in the third year of the grant, this situation has not yet changed.[27] Most commonly, Roma are only involved in implementing Roma-specific grant components.

Interviewed subrecipients stated that the level of cooperation within the CCM, and between the CCM and PR, was decreasing after the initial preparation and submission of the Round 6 HIV grant proposal. Subrecipients stated that the decision-making about the implementation of certain components, such as the selection of the medical professionals who would perform the testing and health education among the public, did not take into consideration stakeholder input and, consequently, these components are not satisfying the real needs of the community.[28]

Furthermore, civil society was quite critical of the lack of transparency of the HIV/AIDS proposal preparation process for Round 6. Unlike the proposal preparation process for Round 3, which involved all interested stakeholders as active participants, the Round

6 proposal was drafted by several individuals, based upon the documents and proposals submitted by NGOs. Certain groups were excluded from the proposal (including youth, Roma, and prisoners).

In **Romania**, the governance structure appears to follow the GFATM guidelines to the letter as regards broad civil society participation. This, however, has a flipside of becoming too big to be manageable and effective, while at the same time still not making room for minority (Roma) participation. The CCM includes public institutions as well as the private and nongovernmental sectors. Initially, all NGOs, academia, private and other sector representatives that expressed interest were admitted. Pursuant to Romania's *CCM Operation Book*, the process of admitting new members remains open. However, in order for the body to cope with an ever-increasing number of members (presently more than 55) and remain operational and effective, the CCM established an executive committee (with a maximum of 15 members selected from each constituency group on the CCM). The executive committee continues the work of the CCM during the period between its periodic meetings on program implementation. Despite the inclusive nature of the Romanian CCM, Roma organizations are not represented either in the CCM or in the executive committee.

The PR of the grant is the Romanian Ministry of Health and Family, which has a project management unit (PMU) responsible for the administration and evaluation of the projects. Each component of the grant has staff responsible for the overall design and management of projects included in the component.

Subrecipients are from both the governmental and NGO sectors. Initially, no Roma subrecipients were involved in the implementation of the TB project, but later in the process, Romani CRISS was selected as the only Roma subrecipient organization. No Roma NGO subrecipients have been involved in the implementation of HIV projects.

In **Serbia**, the GFATM governance structures initially reflected the realities of the national response to HIV. Accordingly, there were several key health institutions that maintained a leadership role from the very beginning. Civil society involvement followed later, but to date NGOs remain poorly represented on the CCM, although participation of PLWHA on the CCM has always been considered a priority. Acknowledging low representation of NGOs on the CCM, the Serbian CCM formed a working group which developed the National Guidelines for Selection of NGO Representatives to the CCM.[29] Currently there are only four NGO representatives on the CCM. Although one of the four NGO representatives is Roma, it was not clear to other CCM members interviewed for this report that he was there to represent the Roma NGO community.[30] Field research has further shown that Roma civil society is not aware of Roma representation on the CCM, or in fact even aware of what the CCM is.[31]

The PR serves as a "pass-through" mechanism from the Global Fund to subrecipients: it does not benefit financially from the project implementation, and is allocated

a budget only for management staff and equipment for the project implementation unit. The CCM retains overall oversight of the performance under the GFATM grants.

No Roma NGOs have been subrecipients or sub-subrecipients in any round of GFATM grants in Serbia, although some Roma organizations and individuals were involved, informally, in the work of other subrecipients.

The Benefits of Roma Civil Society Involvement in Project Implementation

Field research revealed that activities directed at Roma have greater impact when Roma stakeholders are directly involved in project implementation. In **Bulgaria**, the fact that subrecipients (for Roma components) are mainly Roma organizations is considered a positive aspect of the project. The local Roma NGOs themselves said during the interviews that if there had been no Roma organizations implementing the project it would not have achieved successful results: "Nobody else would want to get into the ghetto and work with Roma."[32] They further stated that having Roma as social workers increased the level of confidence from the community. Similarly, in **Serbia**, engaging Roma key informants proved an effective method of community outreach to raise awareness about TB and HIV prevention and treatment. Key informants were selected from members of Roma communities who had influence within the community; and not only benefited from increased knowledge about HIV/AIDS and TB themselves, but also spread this information throughout their communities and helped to identify more potential key informants.

However, where Roma are not engaged, it can be much more difficult to reach target communities. There were reports from **Serbia**, for example, that some attempts to provide GFATM-supported services were rejected outright, while others were met with distrust from the community.[33]

Barriers to Roma Civil Society Involvement

There is both a real and perceived lack of capacity of some Roma NGOs to take on GFATM projects. In **Macedonia** and **Serbia**, the lack of capacity of Roma NGOs was cited by the GFATM project coordinators as a barrier to involving Roma partners as more than sub-subrecipients (in Macedonia),[34] or at all (in Serbia).[35] At the same time, the investment in capacity building to increase Roma NGOs' ability to engage in these processes has been insufficient. In **Macedonia** and **Serbia**, GFATM grants were used to build capacity of Roma NGOs in order to engage them as subrecipients or formal partners. However, to date, these NGOs have remained engaged in project implementation at an informal or sub-subrecipi-

ent basis only, pointing to weaknesses in these capacity-building programs. In **Romania**, where the Global Fund is funding four projects, there is only one Roma NGO subrecipient, which indicates that the Global Fund's impact on development of Roma civil society has been extremely low. In **Bulgaria**, where Roma involvement at the implementation level has been stronger, the rigid structures established by the PR for program management tended to limit Roma NGO autonomy and decision-making power over the implementation of certain activities.

In certain cases, Roma NGOs are reluctant to address issues that carry additional social stigma. In **Bulgaria**, for example, some of the most at-risk groups within Roma communities were not reached, despite the involvement of the Roma NGOs in the implementation. This reportedly was because the community-based implementers feared increasing the already high stigmatization faced by Roma communities and chose not to target Roma from particularly vulnerable groups like sex workers and drug users.[36]

Another barrier to involvement is the widespread misunderstanding that Roma NGOs can only apply for or participate in projects that directly target Roma communities. Principal recipients explained that Roma NGOs were not involved in the implementation of projects targeting vulnerable groups, such as IDUs and sex workers, where some clients are also Roma, because they were not interested in doing so. However, interviewees in all four target countries said they were simply unaware they could apply to implement non-Roma specific project components.

The lack of information about the Global Fund and transparency of CCM processes in the four countries also present barriers to Roma involvement. Across all countries, many of the Roma civil society representatives interviewed did not have a clear understanding of what the CCM is and does. Many of these representatives report learning about the GFATM projects only in the course of implementation, without having had any opportunity to offer prior input.

The Need to Increase Participation and Representation

Even though formally CCMs are meant to be open to a wide range of stakeholders, including civil society, in order to incorporate their varied expertise and experience, the CCMs in all four countries still lack sufficient representation from civil society stakeholders, and particularly Roma. Roma participation has been very limited, or in some cases non-existent, at both the governance and implementation levels. In some cases, the bureaucracies established to manage GFATM grants are insufficiently flexible or sensitive to Roma civil society input. Importantly, extremely low awareness of the CCM among Roma civil society is a serious impediment to its participation and limits the effectiveness of GFATM projects.

Global Fund Impact on the Health of Roma Communities

The Roma components of the GFATM grants have had a positive impact by increasing access to information and services on HIV/AIDS and TB in Roma communities generally. With few exceptions, the national Roma policies do not address HIV/AIDS and TB, or sometimes even health, as priorities. However, this assessment of GFATM grants indicates that the needs of certain groups among the Roma at a higher risk of contracting HIV/AIDS and TB infection, such as sex workers and drug users, are not always being addressed. The GFATM projects are in many instances not based upon reliable data or solid needs assessments and do not clearly identify their target groups. Furthermore, the GFATM projects tend to lack coordination with other related initiatives on Roma health, which deprives the projects of valuable experience and expertise, and ultimately limits their impact.

Proposed Project Activities

In all of the target countries, some or all GFATM projects have proposed components that focus specifically on Roma. This was generally commended as a positive aspect of the GFATM grants.

In **Bulgaria**, the HIV/AIDS grant includes a broad range of activities focused on Roma communities, from research and prevention, to outreach and harm reduction, to training, in 10 localities. These activities include a rapid baseline situation assessment and follow-up assessments on the vulnerability among Roma communities; the development of specific educational materials; training workshops for local outreach workers and peer educators and support for outreach and peer education activities; support for Roma community-based centers, mobile medical units, and local health services; and the distribution of condoms and clean needles and syringes.

The TB grant also includes the Roma community among the most vulnerable groups. This was the result of the analysis undertaken during the drafting of the *National Program for Prevention and Control of Tuberculosis in the Republic of Bulgaria 2007–2011*, which showed that in 17 big cities in Bulgaria, Roma TB patients represent 50 percent of all TB cases (while the Roma population constitutes only 4.8 percent of the general population, according to official data, or about 10 percent, according to unofficial estimates).[37] One objective of the project is: "to improve TB case detection and treatment success among the Roma population." In order to achieve timely discovery and improved cure rates among the Roma community, the project aims to establish a supportive environment by involving Roma

community members and creating health and social centers in Roma neighborhoods. Trained members from the Roma community will be engaged in 28 regional teams to work among the Roma population and provide such services. This model is very similar to the one already operating under the HIV/AIDS project. The grant agreement had not yet been signed at the time of this assessment and as such project implementation had not commenced.

In **Macedonia**, one objective of the HIV/AIDS project is to "prevent HIV transmission among vulnerable groups, including sex workers, young people, IDUs, MSM, the Roma community, and prisoners." Activities supported by the grant include training of peer educators and social/health professionals to reach the Roma community and support for outreach activities.[38]

The TB project does not specify the Roma community as a target group. The planned activities under this project are primarily aimed at reaching "other risk groups," but several activities also cover Roma. These include active case finding (regular fluorography testing, with subsequent hospitalization if necessary) within Roma communities, a knowledge, attitudes, practice (KAP) survey among vulnerable groups, including a representative sample of the Roma population, and education and discussion activities within Roma community centers. Other project objectives may also indirectly reach the Roma community in the long-term, including activities aimed at creating a supportive environment for community TB care and prevention. However it was unclear that activities in these areas were being implemented in Roma communities at the time of this assessment.[39]

In **Romania**, one of the objectives of the Round 2 TB project was to "improve TB control in children and high-risk groups, such as persons infected with HIV, prisoners and Roma." The project proposed to develop a strategy for TB control in Roma communities based on the National TB program and recommendations from EU experts. They also proposed to offer HIV testing to registered TB patients from the Roma community to evaluate the magnitude of TB/HIV coinfection.

The Round 2 HIV/AIDS grant aims to reduce HIV/STI transmission in hard-to-reach communities, including among Roma, by developing appropriate information, education, and communication (IEC) materials and training Roma health mediators to act as peer educators in their communities and to ensure referral to medical and social services.

The Round 6 HIV/AIDS grant envisions community outreach among Roma, including condom distribution, referrals to services, interpersonal IEC delivered via peer education, needle exchange, basic medical and social services, and the establishment of a help line. The grant also includes funding for a behavior surveillance survey to assess vulnerability among marginalized groups. The grant also aims to develop capacity and increase access to voluntary counseling and testing (VCT) among Roma. As an expected outcome, 25,000 Roma will have access to IEC for behavior change, condoms, VCT, reproductive

health and family planning services through community-based organizations, NGOs, and a network of Roma health mediators.

The Round 6 TB project proposes to develop a national health education strategy for vulnerable populations, including Roma. The strategy is intended to be developed by a multisectoral working group, based on information gathered by GFATM subrecipients through KAP surveys. During the grant period, subrecipients will also be contracted to elaborate information campaigns and health education activities that address vulnerable and poor populations, including Roma.

In **Serbia**, Roma were not specifically targeted by GFATM grants until Round 6, when funds in the amount of up to $135,000 per year were allocated specifically for fighting HIV/AIDS among the Roma population. The project aims to establish HIV-prevention services for young Roma people who are at increased risk of HIV infection. The services will be delivered by existing organizations that will need additional training in health promotion and HIV prevention. The capacity building will be conducted by local NGOs that are experienced in peer education and HIV prevention. The proposed activities involve training peer educators and outreach workers, developing IEC material, outreach services with health mediators working to change behavior related to HIV/AIDS risks, referrals for counseling and testing, referrals of pregnant Roma women for HIV counseling and testing, providing prevention of mother-to-child transmission services where necessary, and identification and referral for treatment of HIV, STIs, and TB cases.

Additionally, the HIV/AIDS project is linked with the Round 3 TB project and will start building the capacity of TB outreach workers on VCT.

In the second phase of the Round 3 TB grant (years three to five), the CCM and PR have placed increased emphasis on TB prevention, care, and treatment among the Roma population. The proposed approach includes several models to change high HIV/AIDS risk behaviors using peer education and peer information sharing, Roma health mediators, IEC materials, visits of medical health practitioners from local primary health centers, media and audio-visual materials in Romani languages, and counseling practiced by social workers. The proposed activities are based on lessons learned and experience to date in dealing with health issues among the Roma population.[40]

The activities planned for this phase also include a needs assessment among Roma living in slums and IDPs in collective centers, to be followed up by active screening for persons with TB symptoms and for children under 14 years of age. Intensive health education campaigns and specially organized health education sessions will be carried out by health staff involved in TB control and by local NGOs, with the support and collaboration of religious organizations. An expected outcome is that 50,000 Roma will benefit from the project over a period of five years.

Addressing the Higher Vulnerability of Roma to HIV/AIDS and TB

As mentioned at the beginning of this report, despite limited official data, Roma communities live overwhelmingly in conditions of poverty, often extreme poverty, and experience exclusion in all areas of life. This translates into inadequate housing, lack of education, unemployment, lack of papers, impeded access to health care, and discrimination at the hands of representatives of public institutions, including medical personnel, as well as overall poor health. The vulnerability of certain segments of the Roma population to HIV/AIDS and TB also has its roots in the chronic poverty, exclusion, and discrimination Roma suffer. Accordingly, any initiatives aimed at reducing the negative impact of HIV/AIDS and TB should take into account the underlying causes that increase vulnerability. However, GFATM projects in all countries have been weak in addressing these factors. For example, the GFATM projects in **Macedonia** lack the comprehensive approach essential to making a significant impact on Roma health. Representatives of one of the sub-subrecipient NGOs, Drom Kumanovo, stated that, in their view, the approach taken in the GFATM grant is not comprehensive. According to these representatives, it does not address the issues of key importance for dealing with HIV/AIDS and TB respectively, such as: lack of education, poverty, and insufficient access to health care, as well as certain traditional practices and beliefs, which were reflected in the KAP survey.[41]

As previously discussed, data on Roma health in most countries of the region are virtually non-existent or seriously flawed. The absence of reliable baseline data is a barrier to designing an effective intervention that will reach the most at-risk groups. Moreover, the absence of data does not allow for the impact to be measured and quantified. Consequently, very few GFATM projects were based on valid data or a thorough needs assessment. In **Macedonia**, for example, the data taken as a starting point for the TB project design and development were official statistics. According to these official statistics, Roma account for only 2.66 percent of the country's population. This figure is widely believed to be an understatement, omitting undocumented or unregistered individuals, refugees, and homeless persons, that is, categories which clearly run a higher risk of contracting TB. Accordingly, the GFATM grants in Macedonia most likely do not reach the groups of Roma who are most at risk.

In **Romania**, no comprehensive and coherent needs assessment was conducted prior to the project's implementation. Thus, it is likely that in Romania, too, the GFATM interventions do not reach those most at risk.

In contrast, in **Bulgaria**, one of the obvious merits of the Roma component of the GFATM project has been a thorough and detailed needs assessment undertaken at the beginning of the project. Cities were selected for the implementation of this component after a survey of all 28 Bulgarian municipalities and additional expert analysis of the

accumulation of risk factors in one place or activity such as big and segregated Roma communities, drug use, sex work, main roads, and labor migration. After the selection of 12 most at-risk places, a local needs assessment was carried out by a team of experts in each location to explore the local context. The assessment included interviews with local Roma leaders and community-based organizations, focus groups with young people, and interviews with representatives of municipal agencies and health institutions. This explains the high marks given by many interviewed respondents to the manner in which needs were assessed and the results of the assessment, which reflect the reality of Roma. Roma persons were involved in the needs assessment on different levels, mainly as respondents, but also as researchers.[42]

Another positive practice has been noted in **Serbia**. There, as in most countries in the region, vast numbers of Roma do not have personal documents, and/or live as unregistered residents in the country. Individuals without proper identity documents usually cannot obtain medical services, among other social services. This problem has not been solved yet at the national level. Instead, cases are often solved at the individual level, on a case-by-case basis. The GFATM project activities in Serbia nevertheless provide services for people even without documentation and health insurance.[43]

A significant problem noted in all countries is that the Roma-specific components of the GFATM projects target the entire community, rather than those of its members that are most at risk, as is the case for the majority population. In most of the countries, target communities have been poorly defined, and as a result the most vulnerable members of the Roma communities are not always being reached.

For example, in **Bulgaria**, the results from the national sentinel surveillance carried out in different groups,[44] showed zero HIV prevalence in the Roma communities in 2005,[45] which suggests that persons most at risk are likely to live outside of their communities and thus left out of the project's scope. In the absence of determined target groups, it was left to individual local organizations to see to it that the people most in need were covered by the project activities. Some of the organizations decided to carry out pure prevention and awareness/knowledge raising activities among the general Roma population, while other organizations chose to work more closely with specific groups. The organization in Stara Zagora chose to work with women engaged in so-called "hidden prostitution,"[46] and with migrating MSM. By contrast, some organizations openly declared that they would not work with IDUs or sex workers, but would prefer to engage only in broad health educational and prevention activities within the Roma community in general.[47] Interviews with sex workers from Haskovo, for example, indicate that they have never been reached by the local organization implementing the HIV project component aimed specifically at reaching them, and had no awareness that such a project was being implemented.[48]

Strengthening Coordination to Improve Roma Health

While the projects supported by the Global Fund are coordinated with national HIV/AIDS and TB strategies, they are not coordinated with strategies and policies that aim to improve Roma health and well-being. It was reported in all target countries that the GFATM projects have limited connection with other initiatives to improve Roma health.

In **Bulgaria**, interviews with NGOs that are not implementing GFATM projects but have experience in Roma health programs drew the conclusion that the HIV/AIDS project and its Roma-specific component have weak relations with other major programs on Roma health that are being implemented in the country, such as an innovative program for health mediators. They felt this would detract from the project's long-term sustainability and effectiveness. In **Romania**, where multiple documents and initiatives exist concerning Roma health, GFATM projects were not sufficiently coordinated and harmonized with the activities on the ground, and this was deemed a weakness of the projects.

Stakeholders in all countries felt that GFATM grants could be much more successful at reaching Roma communities, if they were more closely linked with the relevant state policies and programs on Roma health. Roma participation could also be increased, if the GFATM projects drew on the pool of experts and NGOs working to implement these policies, particularly in the area of health. This again calls for more thorough coordination and integration of the GFATM grants in the overall policy framework aimed at Roma. One of the most obvious opportunities to connect the GFATM projects more closely with local and national initiatives involving Roma is cooperation within the framework of National Action Plans for the Decade of Roma Inclusion, as the Decade targets poverty and exclusion and stresses interconnectedness of various factors, including health.

Sustainability

The sustainability of GFATM projects appeared to be an issue of concern to many stakeholders interviewed for this report, particularly where projects have either been completed or are in their final stages. It is also of concern in **Bulgaria** and **Romania**, which are no longer eligible for new Global Fund grants due to increases in gross national income. They suggested that lessons should be learned to correct for these shortcomings in the future, especially since many reported that the GFATM grants in some ways have prompted other donors to reduce or terminate their assistance. Stakeholders suggested that one way to ensure sustainability could be to offer positive inducements, especially on the local level, for authorities to take over and continue the GFATM-initiated interventions, possibly with EU structural funds for new EU member countries. Another, perhaps even more effective measure, would be supporting the development of a strong and involved civil sector to keep the issues on

the political agenda, advocate for increased government funding, and take over and sustain projects with other donor funding after the GFATM funding ceases.

A More Comprehensive Approach for Greater Impact

Roma-specific components of GFATM projects have been a positive aspect of these grants and should be maintained or developed if they are not already included. However, the underlying causes of vulnerability of Roma groups to HIV/AIDS and TB have not been sufficiently addressed in the GFATM projects. The approach furthermore has been on targeting the Roma community as a whole rather than targeting groups at risk within Roma communities, as is the case for the majority population. Such a focus obviously requires research on the at-risk groups in Roma communities, given the scarcity of disaggregated health data on Roma populations, and better elaboration of the target groups. However, research and even careful needs assessments within Roma communities, with few exceptions, have not been done. The impact of GFATM grants on Roma health has also been limited because they have not been adequately harmonized with the relevant national policies for Roma, and their sustainability remains in question.

Notes

1. As of October 2007, individual country reports with translations into national languages are available on OSI´s website at: http://www.soros.org/initiatives/health/focus/roma.
2. This assessment refers to specific groups within Roma communities, i.e. IDUs, sex workers, and the homeless, which—like the same groups within the majority populations—are at higher risk of HIV/AIDS and/or TB. It recognizes social diversity among Roma. By focusing on these particular high risk groups, this assessment does not mean to suggest that all Roma are destitute or prone to diseases.
3. OSI Network Public Health Program, *Mediating Romani Health: Policy and Program Opportunities* (New York: Open Society Institute, 2005): 52.
4. Ministry of Health of the Republic of Bulgaria, *Health Strategy for People in Vulnerable Position Belonging to Ethnic Minorities*. Available at: http://www.mh.government.bg/ (accessed Aug. 13, 2007).
5. World Bank, *About the Roma: Facts and Figures*. Available at: http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/ECAEXT/EXTROMA/0,,contentMDK:20333806~menuPK:615999~pagePK:64168445~piPK:64168309~theSitePK:615987,00.html (accessed Aug. 13, 2007).
6. European Roma Rights Centre (ERRC), Roma Center of Skopje, and Open Society Institute Network Women´s Program, *Shadow Report on the Situation of Romani Women in the Republic of Macedonia*, (November 2005). Available at: http://www.errc.org/db/01/97/m00000197.pdf (accessed Aug. 13, 2007).
7. ERRC, *A Pleasant Fiction: The Human Rights Situation of Roma in Macedonia* (Budapest, 1998).
8. Catalin Zamfir and Marian Preda, *Romii în Romania* (Roma in Romania) (Bucharest: Expert Publishing House, 2002).
9. According to the 2007 Open Society Foundation Romania *Roma Inclusion Barometer*. Available at: http://www.sfos.ro/ro/documente.php?id_document=366 (accessed Aug. 13, 2007).
10. Petar Antić, *Roma and the Right to Health Care in Serbia* (Belgrade: Minority Rights Center, 2004).
11. Government of the Republic of Serbia, "Poverty Reduction among the Roma" in *Poverty Reduction Strategy Paper for Serbia*, Annex I (Belgrade, 2003). Available at: http://www.prsp.sr.gov.yu/ (accessed Aug. 13, 2007).
12. Open Society Institute, *Confronting a Hidden Disease: TB in Roma Communities* (New York, 2007).
13. Tihomir Bezlov and Cas Barendregt, *Injecting Drug Users in Bulgaria: Profile and Risks* (Sofia: Initiative for Health Foundation, 2004): 39–46.
14. Interviews with program staff in Bulgarian cities of Sofia, Plovdiv, Varna, and Kyustendil, January 2007.
15. United Nations Development Programme (UNDP), *Social Assessment of Roma and HIV/AIDS in Central East Europe* (Bucharest: UNDP–Romania, 2004): 45.
16. According to the 2002 official census, there are 53,879 Roma living in Macedonia, which represents 2.66 percent of the total population in the country. See State Statistical Office of the Republic of Macedonia, *Statistical Yearbook and Census 2002*. However, unofficial estimates of the Roma population are much higher: from 150,000 to 200,000 or over 10 percent of the total population according to some sources. See J-P Liegeois, *Roma, Gypsies, Travellers* (Strasbourg, Council of Europe, 1994): 34.
17. Sorin Cace and Cristian Vladescu, *The Health Status of the Roma Population and the Access to Health Services* (Bucharest: Expert Publishing House, 2004).
18. Ibid.
19. Interview with Ministry of Health representatives, Skopje, Macedonia, December 2006.
20. Ibid.
21. Guidelines available at: http://www.theglobalfund.org/pdf/5_pp_guidelines_ccm_4_en.pdf (accessed Aug. 13, 2007).

22. Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), *Distribution of Funding After 6 Rounds*. Available at http://www.theglobalfund.org/en/funds_raised/distribution/#sector_recipients (accessed April 13, 2007).
23. Information in this section is taken from the Global Fund website: http://www.theglobalfund.org/.
24. Interviews with representatives of subrecipient organizations in Bulgarian cities of Pazardjik, Plovdiv, Burgas, Stara Zagora, January 2007.
25. This model is different from the one adopted in some other countries, e.g. Macedonia, where particular NGOs are pre-selected and responsible for the implementation of objectives (components).
26. Interviews with representatives of two subrecipient organizations in Bulgaria, January 2007.
27. Interview with GFATM HIV/AIDS grant coordinator, Skopje, Macedonia, December 2006.
28. Interview with subrecipient MIA-AIDS, Skopje, Macedonia, January 2007.
29. National Country Coordinating Mechanism for TB and AIDS, "Scaling up the National HIV/AIDS Response by Decentralizing the Delivery of Key Services," policy proposal. Available at: http://www.theglobalfund.org/search/docs/6SRBH_1413_0_full.pdf (Accessed Aug. 13, 2007).
30. During interviews, CCM members in Serbia were asked: "Are there any Roma or other minority individuals on the CCM?" The response was: "Currently, none."
31. Interview with Danijela Kocić, coordinator of the Red Cross Serbia, Doljevac, Serbia, January 10, 2007; interview with Osman Balić, NGO YUROM, Niš, Serbia, January 10, 2007; interview with Alberto Isimović, national minority representative of Vranje municipality, Serbia, January 15, 2007; interview with Altena Asanović, office secretary for Roma Issues of Vranje municipality, Serbia, January 15, 2007; interview with Ferhat Saiti, director of TV and Radio Nišava, Niš, Serbia, January 10, 2007.
32. Interview with Anton Karagiozov, chair of the Regional Development Foundation in Plovdiv, Sofia, Bulgaria, February 2, 2007.
33. Representatives from the Roma community reportedly asked providers about what kind of activities they provided and why. When they received apparently unsatisfactory information, they refused the services. See interviews cited in endnote 31.
34. Interview with GFATM HIV/AIDS grant coordinator, Skopje, Macedonia, December 2006.
35. See interviews cited in endnote 31.
36. Interview with Anton Karagiozov, Chairman of Regional Development Foundation in Plovdiv, Sofia, Bulgaria, February 2, 2007.
37. Ministry of Health, Project, "Improving Tuberculosis Control in Bulgaria," project proposal. Available at http://www.theglobalfund.org/programs/countrysite.aspx?countryid=BUL&lang=en (Accessed Aug. 13, 2007).
38. GFATM, *Grant Performance Report for Round 3: HIV/AIDS Component in Macedonia*. Available at: http://www.theglobalfund.org/search/docs/3MKDH_669_288_gpr.pdf (Accessed Aug. 13, 2007).
39. GFATM, *Grant Performance Report for Round 5: TB Component in Macedonia*. Available at: http://www.theglobalfund.org/search/docs/5MKDT_1136_449_gpr.pdf (Accessed Aug. 13, 2007).
40. Viktorija Cucic, *Rapid Assessment and Response on HIV/AIDS Among Especially Vulnerable Young People in Serbia* (Belgrade: UNICEF, 2002), available at: http://www.unicef.org/serbia/Rapid_Assessment_and_Response_on_HIV_AIDS_among_Especially_V.pdf (accessed Aug. 13, 2007); HPVPI Network–Serbia website, *HIV Prevention Among Vulnerable Populations Initiatives*, available at: http://www.hpvpi.org.yu/aboutus.html (accessed Aug. 13, 2007).
41. Interview with representatives of sub-subrecipient Drom-Kumanovo, Macedonia, January 2007.
42. Interviews with representatives of the subrecipient organizations in Bulgarian cities of Plovdiv, Pazardjik, Varna, Sliven, Sofia, Stara Zagora, and Burgas, as well as with project managers, January 2007.
43. See interviews cited in endnote 31.

44. The surveillance is carried out annually among drug users, sex workers, and the Roma communities, as the subjects are recruited through the NGOs, implementing the respective components in selected cities.

45. Ministry of Health, Bulgaria, *Second Annual Program Performance Report for the Period January–December 2005.*

46. The local organization uses the term "hidden prostitution" to define women who do not offer sex regularly as a profession but rather in exchange for different services.

47. Interview with Anton Karagiozov, chair of the Regional Development Foundation in Plovdiv, Sofia, Bulgaria, February 2, 2007.

48. Interviews with nine Roma sex workers, Haskovo, Bulgaria, February 13, 2007.

Public Health Program

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

Engagement with the Global Fund to Fight AIDS, Tuberculosis and Malaria
The Public Health Program works to strengthen civil society engagement with the Global Fund by providing support for efforts to increase the involvement of marginalized populations in country-level Global Fund processes and programs, monitor Global Fund grant implementation at the country level, and strengthen the civil society delegations that sit on the Global Fund's Board of Directors. A number of Soros foundations are also Global Fund grant recipients or partners.

Roma Health Project
The Public Health Program's Roma Health Project supports Roma and non-Roma civil society groups to promote equal access to health services in their communities. Project activities work to build the capacity of government and NGO partners to respond to Roma health needs, advocate for effective health and social service policies, and generate accurate information and media on Roma health issues. The project addresses pressing issues of the Roma community including widespread discrimination and human rights abuses against Roma in health care settings, the high burden of HIV/AIDS and TB, and the dual discrimination faced by Roma women.

www.soros.org/health

Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. 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 a 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 Soros foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

www.soros.org

This report is published by the Open Society Institute as part of its efforts to conduct research and analyses in support of the Decade of Roma Inclusion.

The Decade of Roma Inclusion 2005–2015, an initiative supported by the Open Society Institute and the World Bank, is an unprecedented international effort to improve the economic status and social inclusion of Roma by combating discrimination and ensuring that Roma have equal access to education, housing, employment and health care. Launched in February 2005 and endorsed by nine Central and Eastern European countries, the Decade of Roma Inclusion is also supported by the European Commission, the Council of Europe, the Council of Europe Development Bank, and the United Nations Development Program.

Decade partners are united by a common vision of using a 10-year period to close the gap in welfare and living conditions between Roma and non-Roma populations and to break the cycle of poverty and exclusion that confronts Roma throughout Europe.

The Decade is driven by a commitment to shared values of social inclusion, antidiscrimination, equal opportunity, and abolishing segregation. Central to the values and vision of the Decade is a commitment to embrace innovative approaches, foster international cooperation, and promote transparency.

The Decade of Inclusion places great emphasis on Roma participation. Since its very beginning, the Decade has been marked by Roma representatives and civil society organizations shaping its vision and participating in all of its stages. Roma civil society groups and experts have identified policy priorities and played a key role in defining Decade goals and targets. Continuing and increasing Roma participation, oversight, and monitoring remain a priority and are critical to the Decade's success.

www.romadecade.org

While HIV/AIDS and TB activities supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria have helped increase access to health services for Roma, certain vulnerable groups within Roma communities still lack care and support and face higher risks for HIV/AIDS and TB infection.

How the Global Fund Can Improve Roma Health responds to this problem by assessing the impact of Global Fund sponsored projects and the challenge of delivering HIV/AIDS and TB services to vulnerable Roma groups in Bulgaria, Macedonia, Romania, and Serbia. The report also examines the involvement of Roma civil society in the development of proposals and implementation of projects sponsored by the Global Fund.

The report finds that the overall impact of HIV/AIDS and TB activities is limited because projects have incomplete needs assessments for vulnerable Roma groups or lack coordination with other Roma health initiatives. *How the Global Fund Can Improve Roma Health* aims to close these gaps by providing recommendations to help public health officials and advocates better address Roma health concerns and increase the involvement of Roma NGOs in developing and implementing projects.

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