

Understanding Risk: Roma and HIV Prevention

Countries in the former Soviet Union (FSU) have the fastest growing HIV/AIDS epidemic in the world, HIV infection rates are surging in many parts of Central and Eastern Europe, and tuberculosis is spreading at alarming speed throughout the region. The health, social, and demographic consequences threaten to be devastating. Many Roma and other ethnic minority communities are disproportionately affected by these socioeconomic difficulties compared to the general population, and may be at a higher risk for contracting HIV, TB, and other diseases related to drug use and poverty such as hepatitis.

FACT In many countries, poverty rates among Roma are more than 10 times those of non-Roma. A 2007 UNICEF report found that 66 percent of Roma in Romania live on less than \$4.30 per day and that 53 percent of Roma across the Balkans reported going hungry on a regular basis.

FACT A 2001 study from Slovakia found that Roma women have a life expectancy that is 17 years shorter than that of the overall female population, while the gap for Roma men is 13 years.

FACT Approximately 85 percent of Roma women in Romania report having had only one sexual partner in their lifetime; in comparison, 55 percent of Roma men report more than three partners other than their wives. In most cases, Roma men use condoms for birth control, not protection against HIV/AIDS. Roma men also report using condoms only with one-time partners or with sex workers.

FACT In a 2003 survey, Roma women in Romania were less aware of the means of HIV transmission than non-Roma women. For example, four times as many Roma women did not know that HIV/AIDS can be transmitted by unprotected heterosexual intercourse.

FACT Among 181 Roma injecting drug users tested for HIV at a health clinic in a Roma neighborhood in Sofia, Bulgaria, 11 tested positive for the virus, indicating an HIV prevalence rate of 6.07 percent compared to a rate of less than 1 percent among majority population injecting drug users.

Understanding the risk

Racism and discrimination. Roma experience pervasive discrimination and substandard care when they attempt to access health care services. As a result, many Roma view health care professionals with suspicion and distrust which reduces opportunities for obtaining decent health care. Inadequate communication between patients and providers can delay diagnosis, result in poor treatment support and adherence, and erode overall trust in the health care system.

Roma women as third-class citizens. Traditional social norms often mean that Roma women suffer gender oppression and a lower social status than Roma men. In general, there are fewer social constraints on Roma men having multiple sexual partners, which can increase their exposure to infectious diseases. Roma women are often not



empowered to discuss methods to protect themselves, such as negotiating safe sex with their partner.

Cultural specificities. Some characteristics of Roma cultural traditions can put community members at higher risk for infectious diseases and require that outreach programs are appropriately adapted. Roma communities often have high birth rates resulting in a relatively young population, the demographic most affected by HIV. Taboos regarding sexual issues may make it difficult for Roma leaders and communities to discuss HIV/AIDS and develop effective prevention and treatment programs.

Injecting drug use. Little to no data exists on rates of injecting drug use in Roma communities. The information that is available primarily comes from local organizations working with Roma. In Bulgaria, Macedonia, Romania, and Serbia, groups report increasing numbers of young Roma injecting drugs.

Sex work. Individuals enter into sex work for a number of reasons, some of which may be linked to poverty and lack of employment opportunities. Roma women's particularly low socioeconomic status may make them more inclined to engage in sex work. Staff from an NGO in Macedonia report that in the capital city of Skopje there are increasing numbers of female Roma sex workers and a growing population of male Roma sex workers.

Lack of information. High drop-out rates from school and social exclusion help keep many Roma uninformed about the risk factors associated with HIV/AIDS and TB. Geographic isolation, discrimination, and ineffective communication with health care providers further prevent crucial information from reaching Roma communities.

Lack of documentation. Due to systemic exclusionary practices, many Roma do not have citizenship or required identification documents, often the minimal condition necessary for accessing health insurance and services. A survey in Serbia and Montenegro in 2001 established that over 39 percent of Roma in Serbia lacked basic Serbian identification documents and close to one-third did not possess a health card required to access medical services.

Limited research. Disease surveillance systems across the region have not yet introduced data collection by ethnicity. There is little epidemiological and qualitative research about drug use and sex work in minority communities or prevalence of HIV and TB, particularly among high-risk groups (such as drug users, sex workers, and prisoners). Little evidence therefore exists on which to base HIV/AIDS and TB programs and policies for Roma and other minority communities.

Recommendations

Governments, international agencies, and NGOs should collaborate to add data collection by ethnicity to national census and disease surveillance systems. Complementary epidemiological and qualitative research studies should be funded to examine issues regarding drug use, sex work, HIV/AIDS, and TB in high-risk sub-groups of Roma and other ethnic minorities. Research should be connected to resource distribution and health programs. Members of Roma communities should be directly involved in all Roma-community related research activities. Governments should promote professional education and capacity development for health research among Roma community members.

Governments should support increased training of health care professionals to adhere to human rights principles when treating all patients regardless of race or ethnicity.

Governments, donors, and NGOs should support and implement health programs ensuring that Roma fully understand sexual and reproductive health issues and sexually transmitted infection prevention. These programs must be conducted in cooperation with Roma community leaders, both men and women, as well as Roma social workers and health care providers trained in cultural competence for Roma women's concerns.

Governments should work with Roma NGOs to find solutions to increase access to health care for Roma lacking proper documentation, taking into consideration cultural, social, and human rights issues.

Notes

- 1 UNDP–Romania (2004). *Social assessment of Roma and HIV/AIDS in Central East Europe*. Bucharest, Romania.
- 2 The World Bank (2003). *Averting AIDS crises in Eastern Europe and Central Asia*.
- 3 UNDP (2003). *The Roma in CEE: Avoiding the dependency trap. Bratislava, Slovak Republic*.
- 4 European Commission: Employment and Social Affairs (2004). *The Situation of Roma in an enlarged Europe Union*. Brussels, Belgium.
- 5 UNICEF (2007). *Balkan Roma shunned, illiterate and hungry*.
- 6 Zoon, I (2001). *On the margins: Roma and public services in Romania, Bulgaria and Macedonia*. Open Society Institute.
- 7 UNDP–Romania. *Social assessment of Roma and HIV/AIDS in Central East Europe*.
- 8 UNICEF. *Balkan Roma shunned, illiterate and hungry*.
- 9 Zoon, I. *On the Margins*.
- 10 UNDP–Romania. *Social assessment of Roma and HIV/AIDS in Central East Europe*.
- 11 Ibid.
- 12 Interview with staff members of the Initiative for Health Foundation, Sofia, Bulgaria, August 9, 2007.
- 13 See, <http://statso6.emcdda.europa.eu/en/elements/inftaboz-en.html>
- 14 European Roma Rights Centre (2006). *Ambulance Not on the Way: The disgrace of health care for Roma in Europe*. Budapest: European Roma Rights Centre.
- 15 UNDP–Romania. *Social Assessment of Roma and HIV/AIDS in Central East Europe*.
- 16 Ibid.
- 17 Dekov, V (2007). *Specific Features of the Outreach Work among Roma Population Drug-users in Macedonia* (poster presentation). International Conference on the Reduction of Drug Related Harm. Warsaw, Poland.
- 18 Atanasijevic, M (2007). *Drug injecting in Roma community in Belgrade-Serbia* (poster presentation). International Conference on the Reduction of Drug Related Harm. Warsaw, Poland.
- 19 UNDP–Romania. *Social Assessment of Roma and HIV/AIDS in Central East Europe*.
- 20 Healthy Options Project Skopje (HOPS) (2006). *Harm Reduction and HIV*.
- 21 Schaaf, M (2007). *Confronting a hidden disease: TB in Roma communities*. Open Society Institute.
- 22 European Roma Rights Centre. *Ambulance Not on the Way*.
- 23 Zoon, I. *On the Margins*.
- 24 Ursan, M (2006). *Country Mission Report, Macedonia and Serbia*. Open Society Institute.
- 25 European Roma Rights Centre. *Ambulance Not on the Way*.



OSI supports the Decade of Roma Inclusion.