RUSSIA’S EPIDEMIC GENERALIZES: HIV/AIDS AMONG WOMEN AND PROBLEMS OF ACCESS TO HIV SERVICES IN THE RUSSIAN REGIONS

KATYA BURNS

The National Council for Eurasian and East European Research
2601 Fourth Avenue, Suite 310
Seattle, WA 98121

TITLE VIII PROGRAM
Project Information

Principal Investigator: Katya Burns
Council Grant Number: 821-02f
Date: February 19th, 2007

Copyright Information

Individual researchers retain the copyright on their work products derived from research funded through a contract or grant from the National Council for Eurasian and East European Research (NCEEER). However, the NCEEER and the United States Government have the right to duplicate and disseminate, in written and electronic form, reports submitted to NCEEER to fulfill Contract or Grant Agreements either (a) for NCEEER’s own internal use, or (b) for use by the United States Government, and as follows: (1) for further dissemination to domestic, international, and foreign governments, entities and/or individuals to serve official United States Government purposes or (2) for dissemination in accordance with the Freedom of Information Act or other law or policy of the United States Government granting the public access to documents held by the United States Government. Neither NCEEER nor the United States Government nor any recipient of this Report may use it for commercial sale.

* The work leading to this report was supported in part by contract or grant funds provided by the National Council for Eurasian and East European Research, funds which were made available by the U.S. Department of State under Title VIII (The Soviet-East European Research and Training Act of 1983, as amended). The analysis and interpretations contained herein are those of the author.
Executive Summary

Russia's HIV/AIDS epidemic is generalizing: Infection is moving out of high-risk groups—in Russia's case, predominantly injecting drug users or IDUs—to invade the general population. Rising female infection rates signal the onset of a generalized epidemic in Russia. Throughout the 1990s, the bulk of HIV infection occurred among young men who contracted the virus by sharing contaminated needles which they used to inject heroine. At the turn of the millennium, men accounted for 80 percent of HIV infections in Russia, and 95.6 percent of HIV infections were contracted via contaminated injecting equipment.¹ All that has changed. In 2005, 43 percent of new infections occurred among women of reproductive age and women made up 70 percent of those Russians infected via sexual transmission; at the same time, infection via needle sharing in Russia dropped to 66 percent.² The trend is evident: Young women in their child-bearing years are increasingly becoming infected through sexual contact. Whether or not Russia addresses HIV vulnerabilities among this group of women, therefore, spells the difference between generalized epidemiological disaster and stabilization of the epidemic.

² UNAIDS/TPAA, p. 12 and p. 6.
Russia's HIV/AIDS epidemic is generalizing: Infection is moving out of high-risk groups—in Russia's case, predominantly injecting drug users or IDUs—to invade the general population. Rising female infection rates signal the onset of a generalized epidemic in Russia. Throughout the 1990s, the bulk of HIV infection occurred among young men who contracted the virus by sharing contaminated needles which they used to inject heroine. At the turn of the millennium, men accounted for 80 percent of HIV infections in Russia, and 95.6 percent of HIV infections were contracted via contaminated injecting equipment. All that has changed. In 2005, 43 percent of new infections occurred among women of reproductive age and women made up 70 percent of those Russians infected via sexual transmission; at the same time, infection via needle sharing in Russia dropped to 66 percent. The trend is evident: Young women in their child-bearing years are increasingly becoming infected through sexual contact. Whether or not Russia addresses HIV vulnerabilities among this group of women, therefore, spells the difference between generalized epidemiological disaster and stabilization of the epidemic.

By most counts, the Russian epidemic has already generalized: Between 1 and 1.5 million Russians are infected with HIV today, attaining the 1 percent prevalence marker widely accepted as an indicator of generalization. To stave off impending calamity, Russia needs programs specifically geared to sexually active young women—the wives and sexual partners of injecting drug users (IDUs). Yet, despite a growing realization that the epidemic has mutated beyond the IDU community, the eyes of the Russian government—as in most countries on the

---


4 UNAIDS/TPAA, p. 12 and p. 6.
cusp of generalized epidemic—remain fixed on high-risk groups. Not only is there a dearth of programs specifically for women, there is little understanding of the needs of this newly vulnerable group let alone ways to address them.

This study constitutes one attempt to begin addressing the knowledge gap. It investigates the challenges women face accessing prevention, care and support, and treatment services, in two regions of Russia: Nizhny-Novgorod, a region classified as "medium prevalence," and Sverdlovsk, an "extremely high" prevalence region. At the end of 2005, Nizhny-Novgorod had an official prevalence rate of 112 people per 100,000 (4350 people), and the figure for Sverdlovsk stood at 567.7 per 100,000 (26,474 people—second only to Moscow and St. Petersburg). Since 2002, both regions report stabilization in the total numbers of new infections, but among women, the numbers are growing: In 2004, 39.2 percent of new infections in Nizhny Novgorod oblast occurred among women—up from 15.6 percent in 2000, and in Sverdlovsk, women accounted for 42.2 percent of new infections—more than double the percentage for 1999. Accurate figures for HIV infection are notoriously difficult to come by, and Russia's case it particularly grave: Russia lacks an adequate sentinel surveillance system to monitor the progress of the epidemic. None the less, the trends suggested by the Nizhny-Novgorod and Sverdlovsk figures are clear and disturbing: Even if, as the figures suggest, the

---

5 Medium prevalence regions are those with 51-150 people living with HIV/AIDS (PLWHA) per 100,000 population. Extremely high prevalence regions are those with 301-756 PLWHA per 100,000.
8 Figures for both regions from the World Bank Russian Regions Report 2006, Project on Prevention, diagnosis, and treatment of TB and AIDS, Sverdlovsk report (data from 4) and Nizhegorodskii report (data from p. 2).
epidemic is coming under control, still, the numbers of newly infected women are growing—and this holds true as much for lower prevalence regions as for those in the high-prevalence zone. Indeed, the comparative figures from these two regions suggest that the epidemic is generalizing more quickly in a low-prevalence region than in a high one. This in turn suggests that high-prevalence regions—rather than the low ones that view themselves as relative successes—may actually provide a more effective model for dealing with the generalizing epidemic in Russia.

Evidence from the two regions points to four factors that together adversely impact the access of people living with HIV/AIDS (PLWHA), and HIV+ women in particular, to prevention, care and support, and treatment services. They are: an inadequate administrative framework, both at the level of regional government and among non-governmental organizations; poor understanding about HIV/AIDS and lack of support for PLWHA among medical practitioners; economic and social gender differentiation that increases women's vulnerability to unsafe sex; and stigma and discrimination against PLWHA in general and women in particular, due to association with drug use, conservative political forces in educational and religious institutions, and the policies of powerful foreign donors—notably the United States—that emphasize abstinence over safe sex and oppose harm reduction measures such as needle and syringe exchange.
Administrative Support: Regional Government and NGOs

Both Nizhny-Novgorod and Sverdlovsk suffer—albeit in different ways—from a number of administrative ailments within the regional government that hamper their ability to effectively reach PLWHA and have resulted in a weak programmatic focus on women in particular. To their credit, regional administrators in both oblasts have come to the realization that dealing with the AIDS epidemic requires the involvement of a broad range of sectors—including not only administrative divisions charged with health issues, but also those dealing with social and labor issues, divisions working with women and children, representatives from the non-governmental sector, and PLWHA themselves. Between 2000 and 2005, Sverdlovsk oblast took a number of important administrative steps to coordinate the response to HIV/AIDS across sectors, but in early 2006, these efforts began to unravel in the face of an administrative ordinance from Moscow—a new law on local self-government—that resulted in the virtual collapse of regional government-level funding and coordination mechanisms geared towards the epidemic. Thus Sverdlovsk’s administration made solid progress towards addressing the epidemic for the first few years on the new millennium. In Nizhny-Novgorod, conversely, little substantial effort was made to develop a coordinated response until 2006, and that coordination effort is still in its formative stages. Currently fragile administrative structures in both regions have contributed to weak institutional support for the new wave of infection—among women. However, the relative
success of Sverdlovsk's prior efforts has facilitated the development of several important support networks for women, primarily in the capital city of Ekaterinburg, and Sverdlovsk's efforts, despite their current disarray, suggest an administrative way forward as the epidemic generalizes.

**Nizhny Novgorod: A Slow Response**

Until 2006, efforts within Nizhny-Novgorod's regional government to confront the HIV/AIDS epidemic centered around the Department of Health and focused almost entirely on the medical aspects of the contagion—primarily testing. The administration made efforts to expand the numbers of people required to undergo testing beyond those groups required by Federal Law—prisoners, blood-donors, army conscripts, foreigners residing in Russia for more than 3 months, people undergoing surgery, and pregnant women. As early as 1996, the regional administration passed a decree "On Strengthening Measures for HIV/AIDS Prevention in Nizhny-Novgorod Region," (Decree No. 203), that made testing mandatory for "drug users, people suspected of using drugs, homosexual and bisexual individuals, prostitutes, and individuals having random sexual intercourse." Nizhny-Novgorod passed its own HIV/AIDS Law, "On the Prevention of the Spread of HIV Infection on the Territory of Nizhnegorodskii oblast," on August 26, 2004, and also developed a series of regional programs, the most recent covering the period 2006-2010. While not specified in law, the categories of people required to undergo testing in the oblast have expanded over the years to now include government workers and school teachers (especially kindergarten teachers). Such cross-sectoral coordination as existed up to 2006, focused on coordination with law enforcement—particularly in connection with drug use, and incarceration.

Efforts at coordination to address the social issues surrounding HIV contagion—poverty, stigma and discrimination, support for PLWHA—arose in earnest in 2006, primarily as a result of an internationally funded

---

10 Russia's Federal Law on AIDS was passed on March 30, 1995.
project on "Inter-leadership coordination to counter the spread of HIV/AIDS," supported by the U.K.’s Department for International Development (DFID). The project established an inter-agency working group comprised of representatives from a number of regional government ministries, doctors, law enforcement, as well as NGOs and PLWHA. The establishment of this group takes an important step towards addressing the broader issues surrounding contagion.

This new group aside, however, the administrative structure of Nizhny-Novgorod's response to HIV/AIDS remains hampered by an overly medical focus: The bulk of decision-making power and financial resources dedicated to the regional response is concentrated in the hands of the Regional AIDS Center, with little or no funding going for outreach into IDU and PLWHA communities, and weak coordination with the region's struggling NGO community. According to local activists and PLWHA, the AIDS Center consciously eschewed contact with NGOs working in the area of HIV/AIDS, until early 2006, when it came under pressure from the Global Fund to Fight AIDS, Tuberculosis, and Malaria—a large Geneva-based granting agency that has awarded the Russian Federation funds for anti-retroviral drugs—to included NGO representatives in its deliberations.12

The concentration of power in the hands of the Regional AIDS Center has adversely affected Nizhny-Novgorod's nascent NGO community, which is almost entirely dependent on foreign funding, and, at least until recently, has virtually no say in regional political decision-making. With nearly 50 percent of registered PLWHA in the region, the capital city has only two support groups, and one hotline, for PLWHA—one housed at an NGO, and one at the Regional AIDS Center. There are no programs geared to women, and little effort to reach out into the community of newly infected women, the bulk of whom contracted the virus though sexual contact. As a result, even those support networks that are in operation have largely failed to attract the new predominantly female cohort of polovychki—those who were infected through sexual transmission. Participants in these support groups report that polovychki are generally uncomfortable attending group meetings because they feel that they have little in common with the IDUs and ex-IDUs who dominate the meetings, they fear the stigma of association with IDUs, and they are in general, unwilling to reveal their status. As a result, the new polovychki often bear the burden of their infection alone, not availing themselves of local resources which they feel are unsuited to their needs. This state of affairs bodes ill for the increasing numbers of young women infected with the virus, and poses a significant obstacle

12 Author interviews in Nizhny-Novgorod, Spring 2006.
to accessing these women with prevention, care and support, and treatment services in the months and years to come.

**Sverdlovsk: A Strong Start**

Unlike Nizhny-Novgorod, Sverdlovsk oblast realized early on the need for strong inter-sectoral political leadership. Faced with a burgeoning epidemic among the region's IDUs—the oblast lies at the intersection of five major drug-trafficking routes—in 2000, the administration of Ekaterinburg city set up a special division charged with "coordinating work on prevention and the struggle against drug addition." The division devoted a great deal of its resources to HIV prevention, including providing funding for harm reduction (needle exchange and distribution) to local NGOs, and reaching out beyond the city confines to groups and networks across the oblast involved in HIV/AIDS work. This department was the first of its kind in the Russian Federation, and it inspired the establishment of similar administrative divisions in Perm (2003) and Stavropol (2006).

In addition to its own work, the division coordinated its activities with the City and Regional AIDS Centers (unlike Nizhny-Novgorod, Ekaterinburg housed two AIDS Centers—one city-level, and one regional), and large local NGOs. As a result, the NGO network in Sverdlovsk is considerably more developed and better funded—and consequently more effective—than that of Nizhny-Novgorod. Ekaterinburg boasts some half dozen distinct support groups for PLWHA, including two for women and one specifically for pregnant women. The region's most developed HIV NGO, *Novoe Vremya*, has its own offices complete with special meetings rooms and childcare facilities. It runs a hotline, organizes its own outreach programs—including door-to-door needle distribution for IDUs, works in prisons, women's prisons, and pre-trial holding facilities, and provides training, support, and advocacy services at orphanages that take HIV+ children.13

The supportive institutional structure provided by the city administration and NGOs such as *Novoe Vremya* began to come under fire in 2004, however, under the influence of an organization called "City without Narcotics." City without Narcotics drew its support from members of the city duma opposed to drug use, as well as from influential local members of the Russian Orthodox Church, and arose as a response to the proliferation of drug use across the region. It employed a number of unorthodox detoxification techniques, including shackling IDUs to

---

13 This information drawn from author's interviews at *Novoe Vremya* in April and May 2006.
radiators or beating them until the promised not to take drugs again. Despite these brutal techniques, the organization developed a political following, and a reputation for "getting the job done."

A further blow to Sverdlovsk's nascent administrative support structure came in 2006, when a new federal law on local self-government resulted in the complete restructuring of its AIDS Center facilities and the removal of the division on coordinating work on prevention and the struggle against drug addition from the jurisdiction of the city government—to be placed under the regional administration. As a result, the division lost all its funding—and its ability to support the local NGO community. At the same time, the Regional AIDS Center took over the functions of the City AIDS Center, resulting in administrative chaos. People coming for HIV testing from across the oblast were required to report to the offices of the City AIDS Center, which consequently suffered from a perennial shortage of equipment. Tests were delayed, or never performed, test results were misplaced, and new charges were levied for testing—this despite a federal ordinance mandating that testing should be performed free of charge, and despite the fact that 2006 saw an influx of HIV funding from the Global Fund and the World Bank, and a ten fold increase in the Russian Federal budget for HIV/AIDS.

The conservative bent to regional politics symbolized by City without Drugs and its supporters, in conjunction with the administrative chaos that reigned in the AIDS Center, meant that 2006 saw a gradual deterioration of services for IDUs and PLWHA in Sverdlovsk oblast. It remains to be seen whether or not this trend continues—once the dust of administrative reshuffling clears. For the time being, however, support for infected women—and for the new wave of young women infected via sexual transmission—remains comparatively high in Sverdlovsk.

**Medical Practitioners**

PLWHA—men and women, IDU and *polovychki*—across both Nizhny-Novgorod and Sverdlovsk, universally expressed dismay at the treatment they received from medical practitioners in the course of their diagnosis, care and support, and treatment. There was no evidence that doctors in one region performed significantly better than those in another. In many instances, mistreatment affected PLWHA in a fairly uniform

manner—regardless of gender or method of infection. However, in some specific areas—most notably during pregnancy, women living with HIV/AIDS experienced added discomfort and discrimination.

The problems began for PLWHA from the moment of testing. The AIDS Centers in both oblasts claim that they offer pre- and post-test counseling for every individual who comes to be tested. In both oblasts, however, no PLWHA reported receiving pre-test counseling. As a result, those who tested positive often reported going into a state of shock. Post-test counseling is required for those who test positive, but the bulk of that counseling was completely inadequate. As one young women in Nizhny-Novgorod reported: "When I tested positive, I was completely shocked. I was told to go see a counselor. When I met the counselor, she said: 'You are infected with HIV. Please be advised that knowingly spreading HIV is a criminal offense under Russian law. If you have unprotected sex and spread this virus, you will be incarcerated. Sign this document to show that you have understood.' That was all the counseling I got. When I got out in the hallway, I thought I would faint. I didn't know anything about ARVs [anti-retrovirals]. I found out about them only last year when I was in Moscow."¹⁵ (This woman had been positive for nearly a decade). Post-test counseling services in Sverdlovsk were considerably better than this, but pre-test counseling—performed not by a counselor but by a medical doctor, was similarly perfunctory, ill-preparing those testing for the possibility of a positive result. Experiences such as these alienated PLWHA from the AIDS Centers, and discouraged them from returning to monitor the progress of the infection, or to seek anti-retroviral treatment.

A further common problem, particularly in Sverdlovsk oblast, was the difficulty people who underwent testing faced in obtaining the results of their test. This was especially the case for those who tested outside the regional center, in small health centers or polyclinics. In many instances, PLWHA reported that the clinic at which they had tested had told them results would arrive in the mail. When those results did not arrive, the person who tested let the matter rest. Later, when they developed symptoms or were required to visit the Regional AIDS Center for testing, they were told that their name had already been registered at HIV+. One such individual in Sverdlovsk, for example, reported finding out his status one and a half years after his initial test outside the regional capital. Thus small clinics outside urban centers routinely sent positive results to the AIDS Center, but fail to inform

¹⁵ Author's interview in Nizhny-Novgorod, Spring 2006.
the testees themselves. This practice encourages transmission of the virus, because it does not allow for PLWHA to take precautions against transmitting it to others.

In addition to experiences such as these, women who were HIV+ repeatedly reported stigmatization by health care providers during pregnancy, most notably pressure to abort. The experience of one woman from Nizhny-Novgorod is typical of this trend: "When I became pregnant, I knew I was positive, so I went to the doctor at the AIDS Center. He told me that the baby would have AIDS and die, and that I should abort immediately. He told me that I would die soon too, so that I would not be able to care for my baby. I knew it wasn't true and told him I would not abort. He examined me, and told me that the fetus was already dead. He told me to get a uterine scrape immediately. I did not believe him. I borrowed money from my parents and went to a private doctor. That doctor told me that the fetus was fine. I took the results of that doctor's examination back to the AIDS Center and showed them to the first doctor. He didn't say anything. I never go to the AIDS Center now, except to pick up my ARVs." Experiences such as these discourage HIV+ women from seeking medical advise during pregnancy, thereby increasing the likelihood of mother to child transmission.

Women who are uneducated about HIV transmission are particularly vulnerable to the pressures of medical practitioners, and this is especially the case with married women, who are less likely than female IDUs to have knowledge of HIV, and more likely to listen to medical advise from their doctors. As one doctor in Nizhny-Novgorod reported: "Married women who are infected are more likely to listen to the doctor and go ahead with an abortion. Narkomanki [female IDUs], well you know, they don't listen to anyone. They are always asking questions." One married woman in Sverdlovsk, for example, related the following story: "I found out about my status when I became pregnant. I contracted the virus from my husband. When I saw the doctor, he told me I had to abort and that HIV+ women could not give birth to healthy children. I listened to him and had the abortion. Later I found out about ARVs that can prevent mother to child transmission. I got very depressed. A few years later I became pregnant again. This time I did not go to the doctor. What's the point? I waited until my eighth month to go see the doctor. I knew by that time it was too late for them to force me to have an abortion. My baby was born

---

16 Author's interview in Nizhny-Novgorod, Spring 2006.
17 Author's interview in Nizhny-Novgorod. Spring 2006.
healthy. I don't trust doctors anymore now." Here again, the unwillingness of medical practitioners to interact with HIV+ mothers-to-be, discouraged a woman from seeking medical assistance, thereby limiting her access to treatment for herself and her baby.

**Social and Economic Gender Differentiation**

Although a growing body of literature addresses the impact of social and economic gender differentiation on women's access to HIV services in the developing world, little work has been done on this issue in Russia. Evidence from Nizhny-Novgorod and Sverdlovsk suggests two main ways in which unequal social and economic status affect a Russian woman's access to HIV services: The role she plays within the institution of marriage—particularly her responsibilities for childcare and her vulnerability to violence at the hands of her spouse; and her unequal earning power in the workplace.

Married women who tested positive in both regions reported rejection and, in some cases violence, from their husband once he learned of his wife's status. One woman in Nizhny-Novgorod, for example, reported that, upon learning of her status, her husband beat her badly and abandoned her to care for their small child alone. Another, in Sverdlovsk, reported that her husband became violent and depressed, and she eventually left him. Domestic violence and the fear of domestic violence restrict women's options as they seek care and treatment for HIV and AIDS.

In many instances, women living with HIV/AIDS and counselors working with these women in Nizhny-Novgorod and Sverdlovsk reported that HIV+ women remained with their husbands, even in the face of physical and psychological abuse, because they felt they could not afford to support themselves alone. This was particularly the case in instances where women had children. Those who did leave their husbands often struggled to find the means to support themselves, moving in with aging parents or other family members when possible. In this way, economic dependence and fear of poverty drive women to remain in situations that endanger their health and restrict their access to HIV services.

**Social Stigma and Discrimination**

---

18 Author's interview, Sverdlovsk, Spring 2006.
19 This section based on a series of interviews conducted by the author in March, April, and May 2006 in Nizhny-Novgorod and Sverdlovsk.
Social stigma and discrimination affected all PLWHA across both Nizhny-Novgorod and Sverdlovsk, but women, particularly those infected through sexual transmission, endured additional stigmatization. This arose from two factors: the close association in Russia, of HIV infection with drug use; and prevention campaigns, including those in educational institutions, that eschew discussion of condoms and safe-sex, painting sex as a taboo and emphasizing abstinence over safe sexual practices.

High prevalence rates among IDUs, an emphasis on IDUs in "targeted" HIV interventions, and the virtual absence of public awareness campaigns have together contributed to the perception in Russia that HIV is an ailment that afflicts drug users, but not the general populace. As the epidemic generalizes, this perception has adversely affected access among young sexually infected women. These women are unlikely to attend support group meetings dominated by IDUs, particularly when those meetings are housed at regional "Narcological Institutes," as is the case in Nizhny-Novgorod. This limits their access to support and to information about their infection. Sexually infected young women in both Nizhny-Novgorod and Sverdlovsk also reported mistreatment at the hands of doctors who assumed that they were drug users and demanded a list of everyone with whom they had shared needles. The extent of these reported experiences was greater in Sverdlovsk, where the absolute number of sexually infected women is higher than in Nizhny-Novgorod, but given the dearth of HIV support for women in Nizhny-Novgorod, it appears just a matter of time before these women encounter situations similar to those encountered by their sisters in Sverdlovsk. In this way, stigma surrounding injecting drug use affects not only current and former IDUs, but also those who are sexually infected—predominantly women—thereby limiting their access to services.

Association of HIV with commercial sex work, reluctance to discuss preventative measures such as safe-sex in the media and in educational settings, and political opposition to public awareness campaigns in both regions renders women and girls particularly vulnerable to infection. Biologically, a woman is four time more likely to contract HIV during unprotected sex than is a man from a woman. Thus, poor or non-existent education about safe sexual practices puts women at greater risk of infection than men. The education departments in the regional administrations of both Nizhny-Novgorod and Sverdlovsk were categorically opposed to sex education that discusses safe sex. Education officials in both oblasts bolstered their position by referring to the current U.S. policy on prevention: Abstinence, Be Faithful and (if necessary), use Condoms, or "ABC." Russian education leaders in
both regions indicated their agreement with the American position. As one official explained: "We emphasize abstinence in the high schools. After all that is the American position, and the United States is the most powerful country in the world. They must be right!"\textsuperscript{20} Sadly, the figures suggest that this approach is not working effectively in Russia. In Sverdlovsk, one out of every ten females testing positive for HIV is between the ages of 15 and 17, and the numbers are rising.\textsuperscript{21}

**Conclusion**

Until Russia finds a way to address rising sexual transmission rates among young women, the country will not be able to address the ongoing generalization of the HIV/AIDS epidemic. Evidence from two Russian regions—one medium-prevalence and one extremely high prevalence, suggests that even in regions were infection rates are comparatively low, the epidemic is already generalizing. Indeed, despite recent setbacks, the administrative approach pioneered by high-prevalence Sverdlovsk provides one of the best models for approaching generalization of the epidemic.

\textsuperscript{20} Author's interview in Nizhny-Novgorod, Spring 2006.
\textsuperscript{21} *World Bank Regional Report*, op. cit., p. 2