

Positively Abandoned Stigma and Discrimination against HIV-Positive Mothers and their Children in Russia

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Summary

“Of course I am afraid for my children. I’m very afraid for their future, and how people will relate to them. These children are not dangerous to anyone. They can bring a lot of good to society. The most important question is that of adaptation. Society must adapt to our children and understand that they are valuable citizens. If they happened to experience tragedy, especially as children, then we should be that much more tolerant.”

-Olga Kim, chief doctor of Baby House # 10 (for children of HIV-positive mothers), St. Petersburg, March 18, 2004.

Russia is home to one of the fastest-growing and potentially massive AIDS epidemics in the world, but the government has done little to address the problem. As a result, the Russian public today, though highly educated, is almost as ignorant of HIV and how it is spread as it was ten years ago, when AIDS was hardly known in Russia. A great many medical personnel still remain grossly uninformed and even hostile toward HIV-positive patients. The general public’s knowledge of the virus is, accordingly, extremely limited. And the fact that injection drug users account for 80 percent of persons registered as living with HIV/AIDS does not encourage society to adopt greater tolerance or understanding. There is widespread belief that high-risk individuals—drug users and commercial sex workers—got what they deserved. Recent surveys in Moscow—where there is a higher prevalence of HIV/AIDS and greater access to information than in many parts of the country—revealed that more than half of those responding believe that one can be infected by drinking from the same glass as an HIV-positive person. Even more alarming, nearly half of the respondents believe that HIV-positive people should be isolated from society.¹

It is against this backdrop that a growing number of HIV-positive pregnant women and new mothers must make a very difficult choice: whether or not to keep their children. Shunned by society, these women are vulnerable to discrimination on many fronts: access to health care, employment and education. Many are dependent on drugs and have no access to rehabilitation programs. Still others are living on the brink of poverty. With little or no means to provide for themselves, many find overwhelming the burden of caring for a child to whom the disease may have been transmitted and who would face the same stigma; these mothers may choose instead to abandon their babies.

¹ Greg Walters, “Russia Poll Reveals Severe Lack of Public Knowledge about HIV,” *Moscow Times*, May 17, 2004.

While Russia's HIV/AIDS crisis has received widespread international attention, this particular aspect of the crisis—abandoned children of HIV-positive mothers—still remains hidden behind closed doors. According to statistics from the government's Federal AIDS Center in Moscow, 9,529 HIV-positive women had given birth by January 31, 2005, nearly 80 percent of whom had done so since 2002. Many believe these figures are gross underestimates, and as the virus spreads from the high-risk groups of injection drug users and commercial sex workers to the general population, these numbers are only expected to rise in the coming years.

While most of these children go home with their mothers or other relatives, up to 20 percent may be abandoned by their mothers at birth. This report focuses on the care HIV-positive women receive during pregnancy and the fate of their children—those who go home with them as well as those who are abandoned. These are the children who are being placed in specialized orphanages for HIV-positive children or, even worse, warehoused in hospital wards where their only access to the outside world is a nurse in rubber gloves who feeds them. The isolation of these children has nothing to do with medical science and everything to do with discrimination and stigma—themselves the result of misinformation that the government has done little to reverse. Widespread fear of people with HIV/AIDS has contributed to the abandonment as well as the indefinite segregation of the virus' most hapless sufferers.

While Russian AIDS experts recognize that there is no medical need to isolate these children, some argue that given society's harsh view of HIV/AIDS it is better to maintain separate orphanages for their own protection. Federal Ministry of Health and Social Development² officials recognize that this practice is illegal, and that it reinforces AIDS-related stigma. By law, regular baby houses— orphanages for children three and under—have no right to refuse an HIV-positive child. But the reality is that employees there might be so frightened of daily contact with a baby who might be HIV-positive that they will think of any excuse not to take him, such as closing for repairs or not having enough space.

When a region has no specialized baby house and the regular baby house will not accept an infant who might be HIV-positive, then the child is likely to be left indefinitely in a hospital ward with no stimulation and no opportunity for development. Dr. Yevgeny Voronin, chief doctor of the Republican Hospital for Infectious Diseases, who has been

² In 2004 the former Ministry of Health of the Russian Federation was restructured and renamed the Ministry of Health and Social Development. Throughout this report it is referred to as the Ministry of Health or the health ministry.

treating HIV-positive children for fifteen years, related one particularly horrific case to Human Rights Watch:

We had one case when we got a child who spent three years in isolation in a small children's hospital where everyone was afraid of HIV and everyone was afraid to take that child in his arms. At three the child's development was that of a four-month-old at best. She couldn't speak. She didn't know how to swallow hard food. She was very aggressive and afraid of everyone. She was completely different from our children. I hired an early education specialist and psychologist to work with her alone. We worked with her for a year, but we couldn't change anything. We were then forced—I know it sounds cruel—but we were forced to send her back to the hospital from which she came.³

Compared to such tragic cases, the fate of children born to HIV-positive parents who live at home is a happier one. But their integration into society is far from trouble-free. By the time they reach eighteen months doctors confirm whether they are HIV-positive or negative. If they inherit the virus from their parents, the same fear that keeps many abandoned children stowed away in hospitals may restrict them from entering kindergarten and elementary school. Indeed, some day care centers or educational facilities may even be reluctant to accept a child even if it is the parents—not the child—who are HIV-positive. Such discrimination is not only contrary to Russian law, but to the Convention on the Rights of the Child, which stresses that states take all appropriate measures to ensure that children are protected from discrimination. Despite international and national standards that are supposed to protect the children of HIV-positive women, the Russian government is failing lamentably in its obligation to implement these standards.

In the meantime, their parents may have to deal with belligerent doctors who refuse to treat them. Refusing medical assistance and entry into an educational institution for someone who is HIV-positive may be banned by Russian law, but many people living with HIV/AIDS are so frightened of revealing their status that they would rather suffer the consequences of discrimination than stand up for their rights.

³ Human Rights Watch interview with Dr. Yevgeny Voronin, director of the Republican Hospital of Infectious Diseases, Ust Yezhor, Russia, March 25, 2004.

One HIV-positive woman in St. Petersburg who hides her status from friends and family summed up this awful choice. “We lead a double life. Only among our own can we relax a little.”⁴

Recommendations

To President Putin and the government of the Russian Federation:

- Prioritize HIV/AIDS in public policy. HIV/AIDS must have a visibly higher priority among top government officials, starting with the president. Only with public recognition of the problem can Russia hope to lessen the stigma of the disease. The president and other top officials can help reduce the stigma of HIV/AIDS by addressing the problem publicly, visiting AIDS centers, and increasing funding for public awareness campaigns to educate the public about HIV/AIDS.
- Designate an inter-ministry HIV/AIDS committee to meet regularly and coordinate efforts to ensure Russia’s HIV-positive population has access to the health care, education and job security to which it is entitled under the Federal Law on Prevention of Dissemination in the Russian Federation of the Disease Caused by the Human Immunodeficiency Virus.
- Designate an official body to investigate complaints about violations of the 1995 AIDS law. These would include cases of orphanages refusing to accept HIV-positive children, kindergartens refusing to register children of HIV-positive parents, and HIV-positive patients being refused medical treatment on the basis of their viral status.

To the Russian Ministry of Health:

- Immediately end the widespread practice of segregating babies abandoned by HIV-positive mothers. Babies who require no special medical attention should be transferred to an orphanage within the first days of their lives. Ensure that the level of care these babies are to receive in regular orphanages is equal to that currently provided by specialized orphanages.

⁴ Human Rights Watch telephone interview with “Natasha R.,” St. Petersburg, Russia, June 9, 2004. Human Rights Watch changed the names of those interviewed to protect their anonymity.

- Step up training programs for medical personnel and child care workers in day care centers and orphanages on HIV/AIDS and its transmission, including prevention of mother-to-child-transmission. Health officials need to ensure that HIV-positive women have access to responsive medical care and accurate information about the available means of preventing transmission to their child.
- Establish clear policies and guidelines for city and provincial orphanages to handle the growing number of HIV-positive children.

To the Russian Ministry of Education and Science:⁵

- Set up a task force to deal with the issue of educating HIV-positive children and establish clear guidelines against discriminatory behavior in kindergartens and schools. Abolish the discriminatory practice of barring HIV-positive children and adults from entering kindergartens, schools, technical schools and universities.

To the Local Municipalities:

- End the propiska/registration restriction that limits an HIV-positive woman's access to prenatal and anti-retroviral medications. End the propiska system for HIV-positive children, for whom a transfer to another facility would be in the best interests of their health and development.

To UNAIDS:

- Work with the government of the Russian Federation to improve public education and information about HIV/AIDS prevention, care and treatment, including measures to prevent mother-to-child HIV transmission. Provide technical and financial assistance to train health workers about appropriate antenatal care for pregnant women living with HIV, and to train health workers and orphanage staff on working with children living with or affected by HIV/AIDS.

⁵ In 2004 the Russian Ministry of Education was reorganized and renamed the Ministry of Education and Science. In this report it is referred to as the Ministry of Education or the education ministry.

To UNICEF:

- Assist the Ministry of Education to develop policies and guidelines for the care and protection of the children of HIV-positive mothers within the school system.

Methods

In March 2004, Human Rights Watch traveled to Moscow and St. Petersburg to interview HIV-positive mothers and families, medical personnel and orphanage staff, health officials, social workers and psychologists serving people living with HIV/AIDS, and non-governmental organizations providing material, psychological and legal support for HIV-positive families. Moscow and St. Petersburg were selected because they are cities with high rates of HIV prevalence, and because they are home to the only specialized orphanages in Russia for HIV-positive children.

During the three-week investigation, a Human Rights Watch researcher visited four baby houses:⁶ one regular baby house, two specialized baby houses only for HIV-positive children, and one ward for HIV-positive children located on the grounds of an infectious diseases hospital. The researcher also visited the municipal AIDS centers in Moscow and St. Petersburg, interviewing the directors and other medical personnel there. Several trips were made to Saint Petersburg's Botkin Hospital for Infectious Diseases to speak with patients, medical personnel, and social workers. We also attended a support group for people living with HIV/AIDS and two seminars: one for doctors from the provinces on prevention of mother-to-child transmission (run by AIDS Foundation East-West); the second run by the Moscow School of Adopting Families on the needs of HIV-positive orphans.

For background on mother-to-child-transmission and the plight of Russia's HIV-positive orphans, Human Rights Watch interviewed representatives of non-governmental organizations that focus on prevention of mother-to-child-transmission and/or the welfare of abandoned HIV-positive orphans, including AIDS Foundation East-West (AFEW), American International Health Alliance (AIHA), the United National Children's Fund (UNICEF), Assistance to Russian Orphans (ARO), Transatlantic Partners Against AIDS, Innovations, Delo, Doverie (Trust), Humanitarian

⁶ The term baby house, or *dom rebyonka*, refers to the orphanages for children aged three years and under. These "baby house" orphanages operate under the supervision of the Ministry of Health. After the age of three, the children are sent to a *detsky dom* or children's house, an orphanage for children aged four to eighteen. These orphanages are the responsibility of the Ministry of Education.

Action, Caritas, and the Red Cross. We gathered this information through in-person interviews, over the phone, and from published and unpublished materials supplied by each organization.

Human Rights Watch interviewed a dozen HIV-positive women about their experiences at clinics and during pregnancy and, if they already had children, the barriers they faced in access to health care, day care, and schooling for their child. All of the interviews with HIV-positive women were conducted in Russian, some by telephone and some in person. Most of the interviews were conducted one-on-one except for one group session where six women were present. In each case throughout this report the name of the HIV-positive person interviewed has been changed to preserve anonymity.

Background

The exponential rate with which HIV/AIDS is spreading throughout Russia has already earned the country the distinction among international AIDS experts of being home to one of the fastest-growing epidemics in the world. The official number of registered HIV/AIDS cases in Russia was 311,414 as of March 2005,⁷ but experts reported the actual figures to be much higher. The Federal AIDS Center in Moscow noted that between 800,000 and 1.2 million is a more realistic estimate.⁸ And a United Nations report on HIV/AIDS released in December 2003 set the figure even higher at 1.5 million.⁹ The U.N. estimates that from 1995 to 2001, the rate of new infection in Russia doubled every six to twelve months.¹⁰

Just as the number of newly registered HIV/AIDS cases rises, so too does the number of HIV-positive women having children. HIV can pass from mother to child in utero, in the birth canal during childbirth, and through breast milk. A short course of antiretroviral (ARV) drugs administered to the woman and her newborn can greatly reduce the risk of HIV transmission through these means.¹¹ In 1997, the Russian health

⁷ Federal AIDS Center statistics compiled by AIDS Foundation East-West.

⁸ Human Rights Watch, "Lessons Not Learned: Human Rights Abuses and HIV/AIDS in the Russian Federation," *A Human Rights Watch Report*, vol. no. 16, no. 5, April 2004, p. 9. This report in its entirety was also used to provide general background information.

⁹ Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO), "AIDS Epidemic Update," 2003, p. 14.

¹⁰ United Nations Development Programme, "Reversing the Epidemic: Facts and Policy Options (HIV/AIDS in Eastern Europe and the Commonwealth of Independent States)," UNDP-Bratislava, 2004, p. 16.

¹¹ The World Health Organization recommends prevention of mother-to-child HIV transmission through programs that include voluntary HIV testing of pregnant women, preceded and followed by counseling, and administration of antiretroviral drugs (nevirapine) to the mother before birth (preferably over several weeks, but

ministry began implementing its policy of preventing transmission of the virus from mother to child. In 1997, sixty such births were registered by the government; by the end of 2004, the government estimated that an accumulated total of 9,371 HIV-positive women had given birth in Russia.¹² As with all official AIDS statistics in Russia, there is good reason to suppose these numbers are gross underestimates. While some regions are vigilant about testing all women for HIV during pregnancy, in many areas testing is haphazard or voluntary, and thus it is difficult to know the real numbers. If the actual number of cases of HIV/AIDS in Russia is four times that of the official number, it stands to reason that the number of HIV-positive women giving birth is considerably higher than the reported one.

While the Russian Federal AIDS Center tallies the registered cases of HIV-positive women giving birth, the number of children who are born HIV-positive and remain so is still unclear. This is largely due to testing practices used in Russia that allow doctors to determine a child's HIV status definitively only at eighteen months.¹³ In some areas – Moscow, for example—the age at which the diagnosis is confirmed is even later, at three years of age.¹⁴ This delay in establishing a diagnosis is due to Russia's reliance on an antibody test for the presence of HIV—one that is more available as well as affordable. However, in some of the cities most affected by HIV—among them St. Petersburg—health service providers are trying to use a more costly and more sensitive HIV test to determine a child's status as early as six or seven months. Since in 2004 the majority of HIV-positive mothers had given birth in the past two years, the official diagnosis for the younger children is still pending.

with some effectiveness even in a single dose before birth) and in a single dose to the infant within seventy-two hours of birth. If fully implemented, research suggests that this kind of protocol has the potential to reduce the risk of mother-to-child transmission by more than 50 percent. Joint United Nations Programme on HIV/AIDS (UNAIDS), "Progress Report on the Global Response to the HIV/AIDS Epidemic, 2003," p. 64.

¹² According to Federal AIDS Center statistics compiled by UNICEF and UNAIDS, there were 60 registered births by HIV-positive women between 1987 and 1997. For each subsequent year the figures were: 81 births in 1998; 211 births in 1999; 390 births in 2000; 1139 births in 2001; 2777 births in 2002; 2995 births in 2003; and 1718 births in 2004.

¹³ All children born to HIV-positive women acquire antibodies to HIV, but not all of them are HIV-positive (that is, the virus will not actually replicate in all of them). Most HIV tests that are designed to detect antibodies therefore are not adequate to determine whether an infant is HIV-positive. In the U.S. and much of western Europe, more expensive viral load and other tests are used to determine whether HIV is replicating itself in the infant's bodies, but these are not in widespread use in Russia. Thus, Russian health practitioners are left to wait until maternal HIV antibodies are finally shed by the child, a process that is estimated to take up to eighteen months. See United States National Institute of Allergy and Infectious Diseases, "Backgrounder: HIV Infection in Infants and Children," February 2000 [online] <http://www2.niaid.nih.gov/newsroom/simple/background.htm> (retrieved September 15, 2004).

¹⁴ This period far exceeds the recommended waiting time. See *ibid.*

HIV/AIDS became a problem of epidemic proportions in Russia in the mid-1990s when it began to spread among injection drug users. Injection drug use, dominated by heroin use, grew very rapidly in Russia and many former Soviet states after the collapse of the Soviet Union when unemployment and poverty also skyrocketed. While 90 percent of people officially registered as living with HIV/AIDS as of 2002 were infected by injection drug use,¹⁵ the path of the virus is rapidly moving beyond drug users to the general population. According to a 2004 report by the Russian health ministry, sexual transmission accounted for 19.4 percent of all HIV cases in Russia in 2003, compared to 13.4 percent in 2002 and 4.7 percent in 2001.¹⁶

“Heterosexual contact accounted for around 15 percent of our new cases last year [2003],” said Dr. Vladimir Musatov, deputy chief physician of St. Petersburg’s Botkin Infectious Disease Hospital, adding that the figure was up from 10 percent in 2002. “We have no understanding of a high-risk group here anymore, because the path of infection has spread from the high-risk groups to the general population.”¹⁷ This trend necessarily means a large increase in mother-to-child transmission (MTCT) unless measures are taken to prevent it. If, as experts estimate, the actual number of HIV/AIDS cases in Russia is closer to 1 million, doctors like Musatov are anticipating an explosion in the numbers of HIV-positive women who will give birth in the coming years.

Stigma of Revealing Diagnosis

The ignorance that prevails throughout Russia about the virus—even among the medical community—contributes to one of the biggest problems affecting people living with HIV/AIDS: the stigma they face in society. They are so frightened of revealing the diagnosis of HIV seropositivity that they routinely keep it secret from their employers, colleagues, friends and even their families. They have cause to believe that being openly HIV-positive will lead to their dismissal from work, their ostracism at the neighbourhood clinic, and even being kicked out of their homes by family members. Women who find out they are HIV-positive when they are pregnant must contend with this fear and loneliness on top of the other pressures they face.

Natasha R., an HIV-positive woman in her thirties who attended a self-help group for positive people in St. Petersburg, told Human Rights Watch that people living with HIV/AIDS are so frightened of the consequences of other people knowing their HIV

¹⁵ Human Rights Watch, “Lessons Not Learned,” p. 10.

¹⁶ “Sexual HIV Transmission Sharply Up As IDU Transmission Drops,” Interfax News Agency, April 14, 2004.

¹⁷ Human Rights Watch interview with Dr. Vladimir Musatov, deputy chief physician of Botkin Infectious Disease Hospital, Saint Petersburg, Russia, March 17, 2004.

status that they do not even tell their families. “Hiding your status from parents or spouses is not the exception, it is the rule,”¹⁸ Natasha R. said, citing a woman in her support group who serves as a frightening example for them all. When her husband found out she was HIV-positive he kicked her out of the house and filed a case in court to have her parental rights relinquished. He won, and she was barred from seeing the son she had raised for the first eight years of his life. After her husband kicked her out, her mother also refused to let her in to the apartment to which she has a legal right of residency. With nowhere to go, she lived the life of a homeless person for several months, sleeping in train stations and in the streets until she managed to find an inexpensive room to rent on the outskirts of town.¹⁹

People living with HIV/AIDS are equally frightened of revealing their status at work. At a meeting of an HIV/AIDS self-support group, some members were discussing the dilemma a fellow member was facing. Having applied for a job, she had all but been offered a position when her potential employer asked her to go for a complete medical check-up at a designated clinic. The reaction in the room was swift and unanimous: “She must find someone who looks like her (and who is not HIV-positive) and give her her passport to go and take the medical exam,” said one group member. “That is the only option left to us,” echoed Natasha R. “If she is found to be positive, no one will hire her.”²⁰

Indeed, many are so frightened of the potential consequences of having their HIV status revealed that they quit their jobs rather than risk disclosure. “We learned from one unhappy experience a few years ago. The employer of one of our members, a young man who worked in telecommunications, found out that he was HIV-positive. The company immediately fired him and brought a [civil] suit against him for spreading the disease,” said Natasha R., adding that the man did not live long enough to see the end of the court case. “After that we all slowly left our jobs,” she said. “We lead a double life. Only among our own can we relax a little.”²¹

One place they cannot avoid revealing their status is the local clinic. Once doctors or nurses see their medical records, they immediately learn that they are HIV-positive. People living with HIV/AIDS in St. Petersburg told Human Rights Watch they never know if they are going to meet an understanding doctor or one who addresses them

¹⁸ Human Rights Watch telephone interview with Natasha R., St. Petersburg, Russia, June 9, 2004.

¹⁹ Human Rights Watch interview with Elena S., St. Petersburg, Russia, March 19, 2004. Human Rights Watch changed her name to protect her anonymity.

²⁰ Meeting of a self-help group for people living with HIV in St. Petersburg, Russia, March 19, 2004.

²¹ Human Rights Watch telephone interview with “Natasha R.” St. Petersburg, June 9, 2004.

rudely or refuses to treat them at all. A 2003 study of people living with HIV/AIDS in St. Petersburg, for example, revealed that 30 percent of the 470 survey participants had been refused health care because of their HIV status.²²

But Natasha R. said that she and her friends have found one way to avoid the contemptuous glances and rude treatment at the clinic – they have stopped going there altogether. “We go to our own clinic,” she said, referring to the St. Petersburg AIDS center. In theory, the local clinics are supposed to treat all HIV-positive patients within the district for comprehensive medical care—gynecological, dental, surgery, etc. But since many of these local doctors refuse to treat HIV-positive patients—and many HIV-positive patients refuse to continue to go there—the AIDS center has to pick up the slack. The lines are often very long, says Natasha R., but it is worth it to be able to avoid her local clinic.²³

Irina Annagurbanova, head of the Innovations family center in St. Petersburg, a non-governmental organization funded by international donors, said that many of the HIV-positive people who rely on their support services complain of being turned away by doctors. “We have one woman who needed an operation on her throat, but the doctor refused. We tried and tried to help her find a doctor who would operate, but no one would do it,” said Annagurbanova. “Now we have a woman who needs a heart operation, but again the doctor refused.”²⁴

Since it is illegal to refuse treatment based on the patient’s HIV status, many doctors find convenient excuses to reject a patient. “They might say the operation is optional, or that it is better to wait,” said Tatyana Intigrinova of Transatlantic Partners Against AIDS (TPAA).²⁵

Prospect of Parenthood

If people living with HIV/AIDS face such fears in their everyday lives, their fears only increase with the prospect of parenthood. The discrimination they and their child face may start just days after the birth, when the pediatrician from the local clinic routinely

²² Yuri A. Amirkhanian, Jeffrey A. Kelly, and Timothy L. McAuliffe. “Psychosocial needs, mental health and HIV transmission risk behavior among people living with HIV/AIDS in Saint Petersburg, Russia,” *AIDS*, vol. 17, no. 16, November 7, 2003, pp. 2367-2368.

²³ Human Rights Watch telephone interview with “Natasha R.,” St. Petersburg, June 9, 2004.

²⁴ Human Rights Watch telephone interview with Irina Annagurbanova, director, Innovations Center, St. Petersburg, June 8, 2004.

²⁵ Human Rights Watch telephone interview with Tatyana Intigrinova, Transatlantic Partners Against AIDS, Moscow, June 7, 2004.

makes house calls to all newborns. Many HIV-positive families have reported that these doctors insult them, accuse them of bad parenting, and openly question their long-term ability to care for a child. Some doctors counsel parents not to kiss their babies, and to keep a different set of dishware so as to protect them from infection—advice that reflects their ignorance of how HIV is transmitted. Some doctors refuse altogether to visit a household with HIV-positive people.

These are the barriers HIV-positive children with parents face, but those without parents face even greater hurdles. Some 10 to 20 percent of all children born to HIV-positive mothers are abandoned to the care of the state. These are, more often than not, children of HIV-positive women who are dependent on drugs but have no access to drug treatment programs. The mother not only has no means of seeking help for her addiction, but she is often living on the brink of poverty and barely able to support herself, let alone a child. Furthermore, there is no social support network to enable these mothers to keep their children. In some cases, an HIV-positive mother takes her child home after birth, only to abandon the child later when she finds she is unable to care for him. A significant percentage of these abandoned children—for lack of anywhere else to go—may linger for years in stark hospital wards.

With minimal public funding to counteract ignorance and unfounded fears about HIV/AIDS, it is no wonder that the stigma associated with this disease has led to the disenfranchisement of HIV-positive people—a group whose ranks are growing daily. “Our society is not ready; it doesn’t understand what it’s dealing with,” said Vadim Pokrovsky, head of the Federal AIDS Center. “We spend \$1 million per year on awareness programs. We should be spending \$70 million.”²⁶

On paper, Russian law protects people living with HIV/AIDS from the discrimination they face from a society that fears them. According to the 1995 federal AIDS law, it is illegal to restrict the rights and legal interests of a person living with HIV/AIDS, including in employment, education, and health care.²⁷ But the law, for all its positive points, remains unenforced, and protecting the rights of those living with HIV/AIDS remains a low priority for government officials.

²⁶ Walters, “Russia Poll Reveals Severe Lack of Public Knowledge About HIV,” *Moscow Times*, May 17, 2004.

²⁷ Federal Law on Prevention of Dissemination in the Russian Federation of the Disease Caused by the Human Immunodeficiency Virus, chapter III.

Investigation

I: HIV-Positive Women and Medical Care during Pregnancy

Rise in mother-to-child transmission (MTCT)

As the virus spreads from the injection drug users and sex workers to the general public, the numbers of infected women many Russians perceive to be “socially adapted” are growing. Health care professionals and other service providers interviewed by Human Rights Watch repeatedly categorized HIV-positive women as “socially adapted”—those who have a job and a stable home life and who were not current drug users or sex workers—or “antisocial,” those using drugs, working in the sex trade, or without socially acceptable home lives. The dividing line between the “socially adapted” and the “antisocial” woman may be a fine one, and one that depends on the subjectivity of the doctor treating her. Many women, including those judged “socially adapted,” only discover they are HIV-positive when they go for routine prenatal care, which usually involves an HIV test.

“The pyramid has flipped,” said Nikolai Panchenko, the founder of Doverie (Trust), an NGO for people living with HIV/AIDS that operates on the grounds of St. Petersburg’s Botkin Hospital for Infectious Disease. “If the first wave hit the gay population and then the drug addicts, now a growing percent of new cases is the result of heterosexual contact. A husband who formerly used drugs may infect his wife. She will only learn about her HIV-positive status during pregnancy.”²⁸

The path of the virus may be changing, but the rise in the number of births by HIV-positive women is steady. Vladimir Musatov is deputy director of St. Petersburg’s Botkin Hospital, where all of the city’s HIV-positive women who receive prenatal care are directed for labor and delivery. He told Human Rights Watch that “this tendency is clear beyond doubt.”²⁹ Before 2000 there were only seventy-one recorded cases of HIV-positive women giving birth in St. Petersburg. In 2001 alone, there were 148 such births, followed by 399 in 2002 and 473 in 2003,³⁰ reflecting the national pattern noted above.

Once their medical records confirm an HIV-positive diagnosis, pregnant women are told they must also go to the city AIDS Center for HIV-related care throughout pregnancy

²⁸ Human Rights Watch interview with Nikolai Panchenko, founder of Doverie, St. Petersburg, March 19, 2004.

²⁹ Human Rights Watch interview, Musatov, St. Petersburg, March 17, 2004.

³⁰ Human Rights Watch interview, Dr. Elena Vinogradova, chief physician of the St. Petersburg AIDS Center, St. Petersburg, March 17, 2004.

and beyond. The local gynecological clinic is for general prenatal care, while the AIDS center provides antiretroviral drugs for prevention of MTCT, and addresses other concerns related to HIV. Their diagnosis also frequently subjects them to rude comments and accusations by doctors and nurses in the gynecological clinic, as corroborated by testimony below. Sometimes they are even denied medical care altogether, even though this is a clear violation of the federal AIDS law, which prohibits the refusal of medical assistance to people living with HIV/AIDS.³¹ The United Nations Committee on Economic, Social and Cultural Rights—the expert body that monitors the implementation of the International Covenant on Economic, Social and Cultural Rights—has stated that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds [including health status].”³²

A general ignorance about AIDS and the basic facts of HIV transmission is also found within the medical community. Doctors at gynecological clinics who are uninformed about antiretroviral (ARV) drugs reducing the risk of MTCT also do their patients a great disservice: if an uninformed woman assumes that her child will contract the virus from her, she may decide to abort the child because she does not know about other options. This misinformation may also affect her decision to keep and care for her child rather than to confer custody of the child to the state or another party.

The contempt with which they are, in most cases, treated at the clinic makes some women less inclined to seek medical care altogether. Indeed, many of the so-called antisocial women do not seek prenatal care at all, only showing up at the hospital when they are in labor. According to Dr. Vadim Pokrovsky, head of the Federal AIDS center, one in four HIV-positive women does not have any prenatal care, but bad treatment is presumably only one of the reasons for this.³³ Since many drug-using women in Russia are users of heroin or other opiates, they could easily be helped to stabilize their drug cravings and receive referrals to other health services by being in opiate substitution programs using methadone or buprenorphine, as in many other countries of the world. But in Russia, opiate substitution is illegal,³⁴ closing the door to one of the best hopes for these women. In addition, in a country where injection drug users account for 80

³¹ Federal Law on the Prevention of Dissemination in the Russian Federation of the Disease Caused by the Human Immunodeficiency Virus, Chapter III.

³² International Covenant on Economic, Social and Cultural Rights (ICESCR), “General Comment 14: The Rights to the Highest Attainable Standard of Health,” August 11, 2000, paragraphs 12 and 18.

³³ Remarks from presentation at government meeting by Dr. Vadim Pokrovsky, chief of the Federal AIDS Center, Moscow, Russia, February 2004.

³⁴ Human Rights Watch, “Lessons Not Learned,” pp. 23-24.

percent of the registered HIV/AIDS cases, there are only fifty-nine government drug rehabilitation centers for nearly 4 million drug users.³⁵

The absence in Russia of addiction treatment of the kind that most countries make available leads to situations of profound desperation. Donald Postnov, a doctor at the Moscow-based AIDS Foundation East-West (AFEW) who heads their PMTCT (Prevention of Mother-to-Child Transmission) pilot project, said: “I’ve seen these women [who don’t come for prenatal care]. I’ve seen drug users, commercial sex workers. I was in shock, because it was obvious that these women absolutely did not understand what was happening to them. I saw a woman working on the side of the road with a belly of five or six months, and she was high. As I stood there talking to her she was rocking back and forth. I said, ‘You are pregnant,’ and she answered, ‘So what. I’ll give birth somewhere.’ For these women the dominance of drugs is greater than anything else.”³⁶

In a country where insufficient funding renders long-term ARV therapy accessible to only a small fraction of the HIV-positive population requiring it, pregnant women and mothers of young children are often at the front of the line.

“We do not have the means to treat everyone with ARV, so we have established priorities: women [mothers] and children are given top priority,” said Dr. Elena Vinogradova, chief physician at the St. Petersburg AIDS Center. “First of all, we have to help the mother as much as we can to give birth to a healthy child, and then we have to extend her life as long as possible so that her child does not end up an orphan. This is the main priority in St. Petersburg. While there were problems in past years, this year our city government has responded and given money to cover this priority group.”³⁷

However, some of these HIV-positive mothers are active injection drug users, and are thus automatically rejected from receiving long-term ARV treatment after the birth of their children at AIDS centers throughout Russia.³⁸ “Giving ARV therapy to a drug user is the same as taking money and throwing it into a pit,”³⁹ said Vinogradova, reflecting the view many doctors in Russia have, that active drug users will not follow the required

³⁵ Bill Nichols, “Russian AIDS Workers Wage Battle on Edge of Epidemic,” *USA Today*, April 20, 2004.

³⁶ Human Rights Watch interview with Dr. Donald Postnov, AIDS Foundation East-West, Moscow, March 22, 2004.

³⁷ Human Rights Watch interview, Vinogradova, St. Petersburg, March 17, 2004.

³⁸ Human Rights Watch, “Lessons Not Learned.”

³⁹ Human Rights Watch interview, Vinogradova, St. Petersburg, March 17, 2004.

drug regimen, and therefore the ARV medication will be useless.⁴⁰ Vinogradova's assessment conflicts with that of Dr. Vadim Pokrovsky of the Federal AIDS Center in Moscow, whose research with active drug users has shown that they can comply with ARV treatment protocols as well as anyone else.⁴¹ Pokrovsky's conclusion is echoed in experiences from many countries, where active drug users complied very well, especially where ARV treatment was coupled with other services they require.⁴²

Vinogradova's comment refers to long-term ARV treatment, whereas for short-term administration of antiretroviral drugs to prevent MTCT, active drug users, for the sake of their newborns, are not excluded. There is, however, at least one category of women who are excluded even from receiving short-term ARV: those who do not have a local *propiska* (legal registration of residency). This antiquated registration system affects women who have come from economically depressed areas in search of work or a better life. Some of these women may find employment to support themselves and family members back home, while others are forced by economic necessity to engage in commercial sex work. Without an official relationship to the city supporting the AIDS center, a non-resident requiring ARV medication will be directed back to her city of origin to receive it – not a viable option for many women who cannot even afford the transportation costs. Some of the doctors we interviewed said that access to free ARV therapy for unregistered women is decided on a case-by-case basis: if the woman appears to be “socially adapted,” they would make an exception and offer her care. There are cases of unregistered women receiving ARVs for free, but this is decided by the doctor. If a doctor sees that the woman really wants the pregnancy and is not, in his judgment, “antisocial” (she does not take drugs, she has a job and a family), then he/she may decide to help the patient seek temporary registration in order to receive free ARVs for prevention of MTCT during pregnancy. However, this judgment is a very subjective one. “The border between the perception of a socially adapted and antisocial woman is a fine one,” said Tigran Yepoyan of the Moscow UNICEF office. “It always depends on the person in charge.”⁴³

⁴⁰ Ibid.

⁴¹ Human Rights Watch interview with Dr. Vadim Pokrovsky, director, Federal AIDS Center, Moscow, February 26, 2004.

⁴² See, e.g., Open Society Institute, “Breaking Down Barriers: Lessons on Providing HIV Treatment to Injecting Drug Users,” July 2004 [online] http://www.soros.org/initiatives/ihrd/articles_publications/publications/arv_idus_20040715/Breaking_Down_Barriers.pdf (retrieved September 25, 2004).

⁴³ Human Rights Watch interview with Tigran Yepoyan, Unicef, Moscow Office, March 23, 2004.

Problems at Gynecological Clinics

Many HIV-positive women—in particular those from cities with higher rates of HIV/AIDS, such as St. Petersburg, Moscow and Irkutsk—reported that the attitudes of medical personnel toward them are improving gradually. Nonetheless, many women complained of negative experiences at their local gynecological clinics. These complaints fell into four categories: a) lack of confidentiality of their medical information, b) aggressive behavior and/or refusal of treatment, c) lack of information on HIV and pregnancy, and d) pressure on them to have an abortion.

a) Lack of confidentiality

While doctors and nurses are ethically bound not to discuss an individual patient's information with anyone, those who do are not held accountable for revealing information against the patient's interests. As a result, it is often difficult for a person living with HIV—especially someone who does not live in a big city—to keep his or her HIV status confidential. Often this information slips out without regard for the patient's right to privacy.

One HIV-positive woman living in St. Petersburg told Human Rights Watch that her husband, who did not know she was HIV-positive, went to the St. Petersburg AIDS Center. He had suspected she might be HIV-positive, and asked the doctors to confirm it. There the head doctor told him everything, after which he threw his wife out of the house and filed for divorce. “When I went to the AIDS Center after that to complain about what they had done, I created a storm,” the woman said, adding that they sent her to the psychologist to calm her down, after which the issue was never discussed again. “What can I do?” she asked. “I depend on them for medication.”⁴⁴

b) Aggressive behavior and/or refusal of treatment

In some cases, a woman might find it difficult dealing with the staff at her local gynecological clinic once her HIV-positive status is recorded on her medical documents. One twenty-three-year-old woman who was about to give birth at St. Petersburg's Botkin Hospital in March said this all depended on who was on duty. Some of the doctors and nurses behaved normally, while others were quite rude and neglectful. One nurse refused to give her an intravenous drip when she looked at her medical chart. “She glared at me and said, ‘I'm not going to treat you.’” Another time there was a nurse who

⁴⁴ Human Rights Watch interview with “Vera M.” St. Petersburg, March 19, 2004. Human Rights Watch changed her name to protect her anonymity.

spoke to me in such a way that I still don't like to think about it," she said, starting to cry.⁴⁵

As previously reported by Human Rights Watch [footnote 46], Natalya R., a twenty-six-year-old HIV-positive woman from St. Petersburg, had a similar experience at her clinic:

I went to a city clinic in my neighborhood for a consultation (with the gynecologist). They did the standard tests, including blood tests. I went the second time three or four days later. It was a big scandal. They said I should have warned them that I was HIV-positive. They were shouting, and they pushed me out of there—they said, 'You people know the place where you're supposed to go.' So I went to the AIDS Center, and the gynecologist there saw me and we talked. The gynecologist there called back to the city clinic, and they had a heated discussion. That clinic is close to my house and convenient, but I would never go there again.⁴⁶

If these incidents are at all common in St. Petersburg—a city with a relatively high prevalence of HIV/AIDS as well as one that has had more time and experience to deal with the epidemic—they are probably particularly widespread in the provinces, especially areas where the number of people living with HIV/AIDS is still relatively low.

Take Olga M., a twenty-nine-year-old woman from St. Petersburg who moved to Ivanovo, a city in central European Russia with a population of around half a million. She was diagnosed as HIV-positive in 2000, when she was still living in St. Petersburg. Later she and her husband moved to Ivanovo, where she became pregnant with their first child.

In Saint Petersburg, Olga M. had no complaints about the medical care she received after testing positive. "There everyone knows everything and they treat you better. In Ivanovo it is a big shock for people [when they find out you are HIV-positive.] Here they treat you with malevolence. They are rude to me, force me to wait and make no effort to respect my privacy," said Olga M.. When Olga M. first found out she was pregnant and started going to the local Ivanovo clinic for prenatal care, her treatment began with the doctors pushing her to have an abortion. "They didn't know anything

⁴⁵ Human Rights Watch interview with "Inna S.," St. Petersburg March 17, 2004. Human Rights Watch changed her name to protect her anonymity.

⁴⁶ Human Rights Watch, "Lessons Not Learned."

about antiretroviral medication [to reduce MTCT]. It was up to me to tell them about it.”⁴⁷

c) Right to information

Since many women reportedly only learn they are HIV-positive during pregnancy, the first consultation they receive about HIV and pregnancy is not at the local AIDS center, but at their gynecological clinic. This is a vulnerable time for the patient, and the first consultation is very important. Sometimes doctors talk to their patients about their choices, informing them about available medications that can greatly reduce the risk of MTCT. In some cases, the doctors offer no information other than that the woman must go to the local AIDS center. In such cases, a woman who is not informed about her options may decide to have an abortion, even if she had wanted the pregnancy. According to the two social workers who attend HIV-positive pregnant women at Botkin Hospital—one of two hospitals in St. Petersburg where HIV-positive women go to give birth—more often than not their patients have not been fully informed about preventing MTCT at their gynecological clinics.⁴⁸

“In my experience, about three out of ten women who learn they are HIV-positive during pregnancy are clearly informed [about MTCT] upon receiving the results of their HIV test,” said Vika Tutunik, a social worker with AIDS Foundation East-West who works with HIV-positive women in Moscow. More than half of the women in a support group she supervises have had abortions because they had been poorly informed by doctors about methods to reduce the risk of MTCT, she said.⁴⁹

d) Encouraging abortion

While the practice of doctors putting pressure on HIV-positive women to have abortions was extremely prevalent a few years ago⁵⁰, the tendency to push abortions is slowly becoming less common as doctors are beginning to get information about preventing MTCT. This trend was reported by doctors and social workers as well as by HIV-positive women. Even if some maternity hospitals in Russia first introduced ARV medications to reduce mother-to-child transmission in 1997, it took several years for this information to begin reaching doctors at gynecological clinics.

⁴⁷ Human Rights Watch telephone interview with Olga M., Ivanovo, June 7, 2004.

⁴⁸ Human Rights Watch interview with Lena Gayeva and Anya Mazur, social workers at Botkin Hospital for Infectious Disease, St. Petersburg, March 17, 2004.

⁴⁹ Human Rights Watch interview with Vika Tutunik, social worker with AIDS Foundation East-West, Moscow, March 23, 2004.

⁵⁰ Human Rights Watch interviews with Vika Tutunik, social worker and Dr. Postnov, Moscow, March 23, 2004.

“Now, in Moscow at least, there is less provocation than there was three years ago, when doctors everywhere recommended that HIV-positive women have abortions,” said Tutunik. “I know one woman [in Moscow] who was convinced to have an abortion; to this day she considers it to be a big mistake that she agreed. But when a person is under duress, the influence of those in authority is quite strong.”⁵¹

In provinces where the prevalence of HIV/AIDS has not caught up to the major cities, it seems that encouraging abortion for HIV-positive women during the early stages of pregnancy is more common than in places like Moscow and St. Petersburg. Even in the Irkutsk region, which has the highest HIV prevalence among Russia’s eighty-nine regions,⁵² it is quite common for doctors to urge their HIV-positive patients to terminate their pregnancies, according to one doctor there.⁵³

“We’re slowly starting to see the appearance of specialists who are more tolerant and better trained, but among the circle of doctors there is still a very aggressive group,” that is, doctors who behave in an aggressive or hostile manner toward people living with HIV/AIDS, said Dr. Anna Zagainova, head of the Irkutsk Red Cross center, which offers support services for HIV-positive families.⁵⁴ The most aggressive of all, according to Zagainova, are gynecologists: their behaviour toward HIV-positive women is often rude and verbally abusive. Rather than counselling a pregnant woman who is HIV-positive about her options, they urge her to have an abortion. “Their means of resolving the problem is to try to push a woman [who is HIV-positive] to have an abortion. If she doesn’t want to, they say things like, ‘Just who do you think you’re going to give birth to, and how long do you expect to live, anyway?’” said Zagainova. “Some of our women who know they are HIV-positive and pregnant just don’t go for prenatal care at all until they are beyond the term to perform a legal abortion.”⁵⁵ Since abortion is legal under certain circumstances until the twenty-second week of pregnancy, this means that women who wish to avoid the abortion argument are not seeking prenatal care until well into their second trimester.⁵⁶

⁵¹ Ibid..

⁵² Statistics from the Federal AIDS Center, Moscow, Russia.

⁵³ Human Rights Watch telephone interview with Dr. Anna Zagainova, director of the Irkutsk Red Cross Center, Irkutsk, Russia, June 9, 2004.

⁵⁴ Ibid.

⁵⁵ Human Rights Watch telephone interview, Zagainova, Irkutsk, June 10, 2004.

⁵⁶ With respect to prevention of mother-to-child transmission, the World Health Organization (WHO) emphasizes that while longer prenatal ARV administration may be ideal, even a single dose of nevirapine at the onset of labor will significantly reduce the likelihood of HIV transmission during childbirth. Thus, the children may benefit even when women are seen at a health facility only very late in pregnancy. See WHO, “WHO reconfirms its support for the use of nevirapine to prevent mother-to-child-transmission of HIV,” July 2003 [online] <http://www.who.int/reproductive-health/rtis/nevirapine.htm> (retrieved September 18, 2004).

Those doctors who do exert pressure on their HIV-positive patients to have abortions may be guided by value judgments—they may see anyone who has used drugs to be unstable and unwilling to care for a child. This was the case for one couple in St. Petersburg—both of whom knew they were HIV-positive before they decided to have a family. In spite of the fact that they had not used drugs for several years and were prepared to do everything they could to reduce the risk of transmission to their child, they were repeatedly encouraged to abort the child early in the pregnancy.⁵⁷

In other cases, doctors who encourage HIV-positive women to abort may be guided by ignorance; they simply may not know that there are antiretroviral drugs available to considerably reduce the risk of MTCT. “I have had contact with these doctors [who insist upon abortion],” said Donald Postnov of AIDS Foundation East-West. “But when I ask why, they answer that all HIV-positive women will have HIV-positive children. Then it is clear—this person just doesn’t know. We bring him knowledge [of ARV therapies] and the results of our experience. After that if the doctor still insists on abortion, then the problem is in his head.”⁵⁸

However, Postnov can imagine situations when doctors might be justified in encouraging abortions. For those women who exist on the fringes of society—active drug users and commercial sex workers who do not seek prenatal care—Postnov is not alone in believing that abortions should be encouraged and made readily available. “There are, probably, situations when doctors emphasize abortion. Sometimes this is justifiable, because many drug users who give birth then abandon their children. If there are abandoned children—HIV-positive children—then this is an additional burden for the government,” said Postnov. “If these women will do nothing to ensure a safe pregnancy, then the pregnancy should be stopped.”⁵⁹

Access to ARV drugs for MTCT prevention

While the availability of ARV therapy for people living with HIV throughout Russia is severely restricted by insufficient funding, providing a short course of ARV for prevention of MTCT appears to be a priority of the government throughout the country. To be sure, MTCT prevention regimens vary from region to region. According to Ministry of Health guidelines, which are based on World Health Organization recommendations, HIV-positive women are to receive an ARV drug from the

⁵⁷ Human Rights Watch interview with “Alexei P.” St. Petersburg, March 18, 2004. Human Rights Watch changed his name to protect his anonymity.

⁵⁸ Human Rights Watch interview, Postnov, Moscow, March 22, 2004.

⁵⁹ Ibid.

fourteenth week of pregnancy. In reality, there is no consistency as to when women start receiving the medication. Two factors appear to play an important role in determining when antiretroviral therapy is begun: financial constraints of the local AIDS centers and how willing doctors perceive their patients to be to adhere to the regimen.

Even if an AIDS center claims that it always starts ARVs for MTCT prevention at a certain time during pregnancy, in practice they do not always start the drugs on schedule. In St. Petersburg, for example, one young couple sought ARVs for the woman from the fourteenth week of pregnancy but did not receive them until the twenty-fifth week.⁶⁰

Cash-strapped regional AIDS centers may employ another means of stretching their ARV budgets by requiring their patients to pay for the medication. In Cheliabinsk, for example, where the AIDS Center offers ARV from the fourteenth week of pregnancy, they cannot afford to treat everyone free of charge. In order to bolster supplies, the AIDS Center often asks women to pay for their first prescription of AZT and then provides the remaining drugs free of charge.⁶¹

In theory, ARVs for MTCT prevention are free for all residents who are registered at their regional AIDS center. But given Russia's antiquated *propiska* system that makes it difficult for those who move from other cities to get registered, many people fall through the cracks. Women who are from other regions are not entitled to ARVs at the AIDS center in the city where they live. If a woman who is not registered determines that she is HIV-positive during pregnancy, doctors recommend that she return to her native city to seek medical care. In many cases this is not feasible – the woman may have no opportunity for employment there, or the transportation costs may be beyond her means. Furthermore, even if she does go back “home,” her access to ARVs may not be much better. Given the vast size of the country, regional AIDS centers are scattered at great distances. A woman from the country or a small town may have to travel several hours in order to reach her “local” AIDS center. Once again, time and money are a factor in determining whether or not she will go.

⁶⁰ Human Rights Watch interview with “Alexei P.” March 18, 2004.

⁶¹ Human Rights Watch interview with doctors from the Cheliabinsk AIDS Center (Alexander Vyguzov, Sergei Avdeev and Irina Kostyan), Moscow, March 16, 2004. While private insurers and medical practices have been cropping up since the break-up of the Soviet Union—in which all medical care was free—basic medical services are free for citizens based on their place of residency.

Prenatal Care, Labor and Delivery

As a rule, HIV-positive women who receive prenatal care are sent to a specific maternity hospital—usually part of a hospital for infectious diseases—for labor and delivery. However, there is a significant proportion of HIV-positive women who receive no prenatal care and who only show up at the hospital in the very late stages of pregnancy or during labor. According to medical personnel and social workers, these women are usually injection drug users and/or sex workers; some women do not have a residence permit, and therefore do not have access to free medical care. There is often one designated hospital in each city that accepts women who have no registration and have had no prenatal care. According to health officials, in such cases the doctors on duty are supposed to administer a rapid HIV test to determine whether the woman is HIV-positive; if she is, they administer a single dose of an antiretroviral drug to the mother during labor, and a single dose to the child after birth.⁶² However, in practice many hospitals do not have rapid HIV tests, nor do they have the funding to buy them.

This was the case when Tanya P., a young HIV-positive woman living in St. Petersburg, had her daughter in the fall of 2001. Having had no prenatal care, Tanya P. showed up at a hospital in the suburbs of St. Petersburg when she was in labor. There were no rapid HIV tests available at the hospital where she gave birth, or if there were, one was not administered. Tanya P. said she received no ARVs during labor. She told Human Rights Watch that she was not aware of her HIV status until one month after the birth, when she went for a follow-up visit to the doctor. Her daughter is not HIV-positive, so she no longer needs to go to the AIDS center for testing. Tanya P. is supposed to go every six months; she said she goes “when she has the time.”⁶³

II: Abandoned Children

Care of Abandoned Children

As noted above, in Russia the system of caring for abandoned children is divided between different ministries. The Ministry of Health is responsible for the so-called baby houses, which take in children for the first three years of their lives. After that, children are transferred to a *detsky dom*, or orphanage, the responsibility of the Ministry of Education, where they stay until they are eighteen. Since the health ministry has not established any standard of care for young children abandoned by HIV-positive mothers, the burden of organizing a system of care for this growing number of children is left to the regional authorities. As a result, there are at least three models for the

⁶² Human Rights Watch interview, Vinogradova, St. Petersburg, March 17, 2004.

⁶³ Human Rights Watch telephone interview with “Tanya P.,” St. Petersburg, March 22, 2004. Human Rights Watch changed her name to protect her anonymity.

treatment of such children that vary from region to region. These three models are: sending babies to specialized orphanages for HIV-positive children; sending babies to regular orphanages, where they may or may not be integrated; keeping babies in hospital wards.

Model I: Separate orphanages for HIV-positive children

Whether abandoned children of HIV-positive women should be integrated in regular orphanages or sent to specialized ones is a hotly debated issue in Russia among HIV/AIDS experts and medical personnel. Virtually all health officials who have worked with HIV-positive children believe that these children pose no danger to others in terms of HIV transmission. The rationale for segregating them is usually presented in other terms, such as protection from stigma, convenience to the medical community, and fear on the part of regular orphanage staff.

According to Dr. Elena Vinogradova of the St. Petersburg City Health Committee and City AIDS Center, the specialized orphanage was created in the interests of HIV-positive children, not as a means to isolate them. “We believe these children are like any other. When we created this separate baby house it was to watch over them and protect them until a final diagnosis is clear [at 18 months],” said Vinogradova. When they are all under one roof it is more convenient to observe them, test them, and provide the greatest degree of care, she added. “But as soon as a child leaves the baby house he should go into a regular orphanage. There is no need to build a series of specialized orphanages for these children.”⁶⁴

Her words were echoed by Olga Kim, the chief doctor of St. Petersburg orphanage no. 10, which has been taking in children of HIV-positive mothers since the fall of 2001. “Of course these children should be together until we know for sure if they are HIV-positive. We can watch their immunity levels and determine whether or not they need therapy,” said Kim. “But after that there is no need to send them to a specialized orphanage. These children are not dangerous to anyone and can bring a lot of good to society,” said Kim, adding that two of the oldest children in the facility were transferred in 2003 to a regular orphanage at the age of four.⁶⁵

On the other hand, Viktor Kreidich, the head doctor at the Moscow baby house for HIV-positive children, said that Russia has no choice but to create a parallel system of

⁶⁴ Human Rights Watch interview with Vinogradova, St. Petersburg, March 17, 2004.

⁶⁵ Human Rights Watch interview with Dr. Olga Kim, chief doctor of Baby House #10, St. Petersburg, Russia, March 18, 2004.

orphanages [until age eighteen] for HIV-positive children. “This is not because these children are dangerous for society, but we are dangerous for them,” said Kreidich. “It is considered discriminatory, however, to keep them all together. There are no such cases [of segregated orphanages] in other countries. But our country is wild. Keeping them all together is one way of protecting them from ... society.”⁶⁶

“I have kids up to the age of five,” said Kreidich, who does not know where to send his children who are already beyond the orphanage age. “I raised this issue [with the health ministry] back in 2000. Where are these children going to go later on? No one wants to take them and the Ministry of Health doesn’t want to deal with the problem.”⁶⁷

Yevgeny Voronin, chief doctor at the Republican Hospital for Infectious Diseases in Ust Yezhor (near St. Petersburg), expressed very strong opinions about sequestering children of HIV-positive mothers in separate orphanages. “I am categorically opposed to such an idea,” said Voronin, whose hospital is home to thirty HIV-positive children—some of whom were sent to his institution as early as 1997. “By creating special orphanages we send a message to society that these are not normal children, encouraging the attitude ‘if you separate them, then they must be dangerous.’”

Dr. Voronin believes these specialized orphanages were developed chiefly for the convenience of the medical community, he told Human Rights Watch. This way they don’t have to travel all over the city to attend to children scattered throughout various baby houses. It is also convenient for other baby houses [where they are afraid of HIV/AIDS]; their staff then knows they have no HIV-positive children and therefore have nothing to fear.⁶⁸

As of March 2004 there were only two such baby houses for HIV-positive children in Russia—one in St. Petersburg and the other in Moscow. A second baby house for HIV-positive children in St. Petersburg opened in April.

“The chief doctor at St. Petersburg baby house no. 10 [for children of HIV-positive mothers] is offended. She thinks I don’t like her baby house. I like it and the personnel. It’s not them I oppose, but the system,” said Voronin. “The baby house is full, and so they can’t take in any more babies until they open a second house. But these children are

⁶⁶ Human Rights Watch interview with Dr. Viktor Kreidich, chief doctor of Baby House #7, Moscow, March 27, 2004.

⁶⁷ Ibid.

⁶⁸ Human Rights Watch interview, Voronin, Ust Yezhor, March 25, 2004.

still being born. They are going to need a third and a fourth house. And then you raise another question: if the baby house is for children up to age three, then what? Do we have to create specialized orphanages, and later down the road specialized universities? This policy leads to a dead end.”⁶⁹

According to Alexander Goliusov, who heads the HIV/AIDS department at the Ministry of Health, the policy is not only wrong—it is illegal. “Creating separate baby houses is a violation of the rights of these children. Even if the baby house for HIV-positive children is better than a regular one, it still enforces the stigma society attaches to the disease,” said Goliusov. “Our policy from the very beginning encouraged children not to be isolated, but to be integrated into regular baby houses, kindergartens and schools.”⁷⁰

Goliusov refers to a policy of nonsegregation of children based on HIV status, but the existence of specialized institutions for HIV-positive orphans is no secret, nor is the reason why they were created: because regular orphanage directors were reluctant to take in children with a diagnosis they found frightening. Goliusov said that if a maternity hospital had difficulty convincing a regular baby house to take in an abandoned child of an HIV-positive mother, then it is the hospital’s responsibility to take that baby house to court.⁷¹ However, it is not only unrealistic for cash-strapped hospitals to launch legal battles, it is not the maternity hospital’s responsibility. This point is emphasized by the United Nations HIV/AIDS and Human Rights International Guidelines, which recommend that states “enact or strengthen antidiscrimination and other protective laws that protect vulnerable groups, including people living with HIV/AIDS, from discrimination in both the public and private sectors ... and provide for speedy and effective administrative and civil remedies.”⁷² It is the responsibility of the government—not individual hospitals or doctors—to enforce the law and ensure that these babies are taken to regular baby houses.

Since there is no cooperation among government ministries to help ease the transition from baby house to orphanage and school, the regions are left to struggle to find their own solutions. Why, then, do so many regions choose to segregate these children? “This is based on a fear of the disease—a lack of understanding,” says Goliusov. “But it is illegal for a regular baby house to refuse an abandoned child of an HIV-positive

⁶⁹ Ibid.

⁷⁰ Human Rights Watch telephone interview with Dr. Alexander Goliusov, director, HIV/AIDS Unit, Ministry of Health, Moscow, March 30, 2004.

⁷¹ Ibid.

⁷² United Nations, HIV/AIDS and Human Rights International Guidelines, paragraph 5.

mother.”⁷³ According to Dr. Kreidich and various NGO representatives we interviewed, institutions get around the law by finding other reasons for rejecting a child who is HIV-positive. They might complain that there is no room for that particular age group, or that a wing is being closed for repairs, or that the orphanage is understaffed. This makes it that much harder to prove that they are in violation of the law.

As Golusov pointed out, the conditions at the baby houses for HIV-positive children are, in fact, better than those of the average baby house. But the very existence of such institutions only fuels the fears of society—that these children are in some way dangerous and need to be isolated. Furthermore, by creating a system of specialized institutions for HIV-positive orphans, those babies who are abandoned when the orphanage is full are left in a state of limbo. With nowhere to go until a space becomes available, they are left to linger indefinitely in hospital wards (see section on Model III). It is not in the interests of the child that these baby houses are being created, but rather in the interests of the medical and orphanage personnel. As a result, children are being discriminated against based on their medical status.

This form of discrimination is not only contrary to Russian law, but to the Convention on the Rights of the Child, which stresses in article 2 that states take all appropriate measures to ensure that children are protected from discrimination based on, among other things, the child’s or his/her parents disability, birth or other status. Other status, in this case, is interpreted to include HIV/AIDS status of the child or his/her parents.⁷⁴

Model II: Sending babies to a regular baby house

There appear to be few examples of HIV-positive orphans being integrated into regular baby houses. The model held up by NGOs in Russia as progressive and ideal is that of the city of Samara, where hospitals send children abandoned by HIV-positive women to a regular baby house days after birth. Other examples include Nizhny Novgorod, where the handful of children abandoned by HIV-positive mothers are integrated into regular baby houses.⁷⁵ In Cheliabinsk (in the Urals), children of HIV-positive mothers are also sent to a regular baby house, but they are kept among other HIV-positive children; they do not interact with HIV-negative children.⁷⁶ Even in Moscow, where there is a specialized baby house, children of HIV-positive mothers are scattered in regular baby

⁷³ Ibid.

⁷⁴ Committee on the Rights of the Child, “General Comment 3: HIV/AIDS and the Rights of the Child.”

⁷⁵ Human Rights Watch telephone interview with Viktor Gursky, Human Rights Society of Nizhny Novgorod, Moscow, April 1, 2004.

⁷⁶ Human Rights Watch telephone interview with staff of Cheliabinsk Children’s Hospital #8, Cheliabinsk, April 1, 2004.

houses throughout the city. This, however, does not reflect a change in policy, but a temporary need: in 2003 Moscow's specialized baby house closed for repairs, and they had no place else to send the children. However, since the specialized baby house reopened in March of 2004, the chief doctor received many phone calls from other baby houses asking him to take these children back.⁷⁷

In some cases, once children of HIV-positive mothers are taken into regular baby houses, personnel have expressed fear of catching the disease. Both Dr. Kim and Dr. Kreidich, in St. Petersburg and Moscow, told Human Rights Watch that many caregivers resigned after they learned they would be caring for children who may be HIV-positive. Those who stayed were very cautious around the children for the first month or so, during which time many wore rubber gloves when they had to touch the children. "The first question they asked me was, 'Will I bring this [HIV/AIDS] home to my family?'" Dr. Kim said.⁷⁸

Human Rights Watch witnessed one example of this fear in a regular Moscow baby house that was home to four HIV-positive children. This is a very large orphanage with eighty children who are divided into ten groups, each with their own caregivers. When we accidentally walked into the wrong group looking for a little HIV-positive boy named Gosha, the caregiver said that he was sleeping. She had been away on sick leave for several months, and thus had not been working when the HIV-positive children were transferred to the orphanage. After revealing the nature of the research—babies of HIV-positive mothers—the caregiver's eyes grew round with fear and she immediately started asking: "Who? Who's like that here? Which ones?" When she discovered that the Gosha in question was part of another group, it was clear she was still alarmed to discover HIV-positive children under the same roof.

With inadequate government funding to educate a public whose understanding of the virus is steeped in ignorance and rumor, the fear of daily contact with someone who is HIV-positive extends far beyond the walls of the baby house. Many ordinary Russians find daily contact threatening—being in the same room, shaking hands, drinking from the same glass with someone who has had similar contact with an HIV-positive person. In one case, an early education specialist who worked part-time at a kindergarten in St. Petersburg and part-time with HIV-positive children was asked to resign from her kindergarten job when people learned of her regular contact with HIV-positive

⁷⁷ Human Rights Watch interview, Kreidich, March 27, 2004.

⁷⁸ Human Rights Watch interview, Kim, March 18, 2004.

children.⁷⁹ Even at the St. Petersburg baby house, where the current staff is extremely caring and interactive with the children, the transition was rocky at first. When the announcement was made that the baby house would be taking in abandoned children of HIV-positive mothers, most of the staff resigned, including the head doctor. In Moscow, Viktor Kreidich has also had trouble employing caregivers. Only after the applicant is invited for an interview does she learn that the job involves HIV-positive children. “Then there is a question as to whether or not she will stay,” Kreidich said.⁸⁰

This fear of HIV/AIDS is perpetuated by the Russian media, which often fuels the public’s fear and ignorance of the disease. One story published in the *Komsomolskaya Pravda* newspaper illustrates this point. The story focuses on a three-year-old HIV-positive orphan who has spent his entire life inside an isolated hospital ward. The report compares the child’s spartan existence to a prison term, but rather than criticize these conditions, the newspaper seeks to justify them. According to the newspaper, the HIV-positive child cannot have contact with anyone who is not wearing a mask or even have any toys to play with because the germs could prove fatal for him. The article even cites inaccurate information to justify the medical community’s reluctance to treat people who are HIV-positive. “It can be difficult to convince a nurse to work with HIV-positive patients,” the article states. “This is all understandable: medical science has still not definitively confirmed all of the means of transmitting the AIDS virus.”⁸¹

Such newspaper reports not only continue to spread false information, but they reinforce society’s discrimination against people living with HIV and the belief that their rights should be restricted. Rather than advocate more humane conditions for abandoned children of HIV-positive mothers, the *Komsomolskaya Pravda* article sees the resolution of this problem in preventing HIV-positive women from giving birth: “Specialists at the Tver AIDS center see their main goal to be the prevention of such children being born. A newborn may only be infected with the virus from his mother, and therefore an HIV-positive woman should think a hundred times before making the decision to have a child.”⁸²

⁷⁹ Human Rights Watch interview, Kuzmina, St. Petersburg, March 25, 2004.

⁸⁰ Human Rights Watch interview, Kreidich, Moscow, March 29, 2004.

⁸¹ Tatyana Tyurina, “Three-year-old Alyosha is deprived of his childhood,” *Komsomolskaya Pravda*, April 10, 2004.

⁸² *Ibid.*

Model III: Keeping infants in hospital wards

The fact that hundreds of infants requiring little or no medical attention are forced to spend the first years of their lives in hospital wards is a sorry reflection of the public's attitude toward these children. While the health ministry declined to give statistics on the exact numbers of abandoned children living in hospitals, Dr. Voronin, who is a nationally recognized expert on the care of HIV-positive children, estimates that as many as half of all children abandoned throughout Russia by HIV-positive mothers linger in hospitals indefinitely.⁸³

A) Best-Case Scenarios: De Facto Orphanages on Hospital Grounds

In cases such as the children's ward at the Republican Hospital of Infectious Diseases at Ust Yezhor, City Hospital no. 3 in St. Petersburg, and Little Stork in Irkutsk, the hospital staff—often with the support of a non-governmental organization—have, to the best of their ability, created conditions to foster the child's early development. They have hired caregivers, psychologists, and early education specialists to offer the children the same program they would have in a baby house. These are de facto baby houses on the grounds of an infectious disease hospital.

The flagship institution of this type is the Republican Hospital for Infectious Diseases where Voronin is director, in Ust Yezhor, just outside of St. Petersburg. Voronin took in the first significant numbers of abandoned babies from HIV-positive mothers in 1997, and it was largely thanks to his efforts that an abandoned wing on the grounds of the hospital was turned into a nurturing environment for abandoned HIV-positive children.⁸⁴

As of 2004, Voronin had been treating children with HIV for fifteen years, ever since the first outbreak occurred when children were infected with used syringes at a hospital. "Ten years ago we fought for every day of life. We thought that if the child lived a month, we'd be happy. We didn't think about their future, their education. As a result, our older children [those who are teenagers now] have been cheated out of an education," said Voronin. He didn't want to make that mistake with the young HIV-positive children in his hospital's care. "We saw once they were getting treatment they would live for many decades. Then it became important for us to see what kind of people they would become," said Voronin. But in the hospital, where they had one nurse

⁸³ Human Rights Watch interview, Voronin, Ust Yezhor, March 25, 2004. This is based on Voronin's research in ten different regions in Russia.

⁸⁴ Ibid. Additional testimony on the creation of the hospital-based orphanage in Ust Yezhor came from Human Rights Watch interviews with UNICEF official Tigran Yepoyan in Moscow (March, 23, 2004) and with Lena Kuzmina of Innovations in St. Petersburg, March 25, 2004.

to care for every ten children, there was no opportunity to provide a stimulating and educational environment. Voronin appealed to the Ministry of Health for funds to start an educational program. “The answer I got [from the Ministry of Health] was: ‘You are a doctor. Your work is to treat them. Their minds are no concern of yours.’”⁸⁵ Finally, Voronin got funding from UNICEF to hire teachers and caregivers, even a music teacher. “The children started changing before our eyes,” said Voronin. “They get their [ARV] medication in the morning, but otherwise this is just like a baby house.”⁸⁶

As a result of his efforts to provide a more stimulating environment for the children in his care, Voronin has created the very type of institution he opposes – one that segregates HIV-positive children from society. His ultimate goal is to find homes for these children, and he is a strong advocate for adoption and a frequent public speaker on the subject. Virtually all of the babies who came to him and were later diagnosed to be HIV-negative have been adopted, but the story is different for his HIV-positive children. He told us: “The most important problem is the search for families—to find parents who will understand these are good children. Each one of these children wants a mother and father. But here it is difficult to make people understand that they have a future. I will continue to talk and talk and talk to convince people that these are normal children and that they need homes. I have been talking for six years—so far with little result. But I’ll keep on talking for a long time.”⁸⁷

Voronin’s institution in Ust Yezhor has served as a model for a few other success stories City hospital no. 3 in St. Petersburg and Little Stork in Irkutsk, Siberia. These institutions, like the one in Ust Yezhor, sought municipal and/or foreign funds to create as nurturing an environment as possible on the grounds of an infectious disease hospital.

B) Worst-Case Scenarios: Lingering Indefinitely in Hospital Wards

Those are the brighter examples—those that also tend to be in the spotlight. But no one shines a light on the worst-case scenarios—the cases of abandoned infants left to linger in stark hospital wards. This is reportedly the fate of many children born to HIV-positive mothers. Deprived of any opportunities for physical and mental development, these children lie in barren rooms; their only contact with the outside world is a nurse in a mask and rubber gloves who comes in to feed and change them. This is all that is required of a nurse working in a medical institution. Sometimes, out of pity for the child,

⁸⁵ Ibid.

⁸⁶ Ibid.

⁸⁷ Human Rights Watch interview, Voronin, Ust Yezhor, March 25, 2004.

the medical staff will go above and beyond their duties and favor the tiny patient with some extra attention, the touch of a hand, or a walk on the hospital grounds.

But even these minor improvements of the child's surroundings depend entirely on the kindness of a nurse or doctor who is already overworked and underpaid. In those institutions where the medical staff is either too frightened of HIV or too overworked to care about the child's future, the damage done to the child's development through neglect is often irreversible.

Dr. Voronin spoke of one such case. A little HIV-positive girl was sent to his hospital after spending the first three years of her life alone in a hospital room. "At three the child's development was that of a four-month-old at best. She couldn't speak. She didn't know how to swallow hard food. She was very aggressive and afraid of everyone," said Voronin.

"She was in a small children's hospital where everyone was afraid of HIV, and no one would hold the child in his arms. I hired an early education specialist and psychologist to work with her alone. We worked with her for a year, but we couldn't change anything. We were then forced—I know it sounds cruel—but we were forced to send her back to the hospital from which she came. We had no choice—she was very aggressive toward the other children."⁸⁸

Lena Kuzmina of Innovations, an NGO in St. Petersburg that provides support and services to people living with HIV/AIDS, recalled an equally disturbing incident. She was contacted by a team of journalists from a small Siberian town who had seen a two-year-old boy in a hospital. The boy, who had been abandoned at birth by his HIV-positive mother, was lying alone, and even the nurses were afraid to come near him. Having heard about Innovations' support of St. Petersburg's City Hospital no.3, they appealed to Kuzmina to have the boy transferred to a more nurturing environment. She located the boy and started processing the paperwork to have him transferred, but St. Petersburg officials refused on the grounds that the boy was not a registered resident of St. Petersburg. With no local *propiska*, or registration, he did not have the right to be treated in a city-funded hospital. (Ironically, the wing of City Hospital no. 3 that cares for abandoned HIV-positive children is funded by international donors.) The matter, Kuzmina says, was dropped after that, and the boy remained where he was.⁸⁹

⁸⁸ Ibid.

⁸⁹ Human Rights Watch interview, Kuzmina, St. Petersburg, March 25, 2004.

The refusal to transfer the boy to a facility that would be far better for his mental development based upon his local residency status is a clear contravention of the Convention on the Rights of the Child, which recognizes every child's right to the highest attainable standard of health, and which calls upon states to ensure that "services are provided to the maximum extent possible to all children living within their borders."⁹⁰

C) Waiting for Instruction

Individually, the case of each child left alone in a hospital room represents a tragic story of a life wasted. Pieced together, these incidents paint a scenario of extreme neglect that borders on abuse.⁹¹

The conditions in which these hospitalized infants live depend a lot on the medical staff. If the director of the hospital and the medical staff are caring and understanding of the children's needs, they will do what they can for them within their limited means. But if they are unwilling to provide that care or hampered by their own fears and misinformation about HIV, the child's needs—beyond the most immediate ones—are neglected. "The rights of these children should not depend on whether or not a bad doctor or a good nurse is working at the hospital," said Voronin. "Their rights must be defended everywhere."⁹²

Indeed, the Convention on the Rights of the Child requires in article 19 that states take measures to protect children from negligent treatment, and goes on to stipulate in article 20 that "a child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State."

In many of these situations—especially in smaller cities with fewer HIV cases—the staff of medical institutions or baby houses reportedly do not know what to do with the child. They, according to one NGO representative, "sit around and wait for instruction from the Ministry of Health."⁹³ In the meantime, the children are at the whim of a haphazard

⁹⁰ Committee on the Rights of the Child, "General Comment 3: HIV/AIDS and the Rights of the Child", paragraph 28.

⁹¹ Human Rights Watch interviewed NGO sources from Voronezh and Tver who reported that abandoned children born to HIV-positive mothers were isolated in hospital rooms. Neither of these cases could be verified by Human Rights Watch, but they follow a pattern of neglect.

⁹² Human Rights Watch interview, Voronin, Ust Yezhor, March 25, 2004.

⁹³ Human Rights Watch telephone interview with Natalya Savicheva, Assistance to Russian Orphans, Moscow, March 30, 2004.

system: their fate is in the hands of medical or city health officials who may either look for a solution or try to hide from one. As long as the number of abandoned children has not reached a critical mass, many local doctors and health officials are content to wait in a holding pattern while the child lingers indefinitely in a hospital room.

“In the regions they point to us [in Moscow and St. Petersburg] and say, ‘Look, they have specialized baby houses for HIV-positive children. We can’t afford to create a special baby house for just a few children, so we’ll keep them in the hospital,’” said Voronin.⁹⁴

These children would presumably not be lingering in hospitals if there were a concerted drive to get them into regular baby houses, together with healthy children. But since orphanage directors are reportedly so often able to find indirect ways of refusing such children, as noted above, there is often no choice but to keep them where they are – in hospitals. That is why city health officials in St. Petersburg and Moscow are proud of their specialized baby houses for children of HIV-positive mothers. These are the showcases they put on display for foreign visitors: the staff is interactive, the toys appropriate and plentiful. “They are happy to show you these baby houses,” said Voronin. “But no one says, ‘Let’s go to the hospitals where half of our abandoned children are lying and waiting for space [in an orphanage].’”⁹⁵

Voronin’s statement that up to 50 percent of all babies abandoned by HIV-positive mothers are left in hospitals is an estimate based partly on his extensive contacts with other health professionals in the country. He is quick to add that there is no national system tracking the fate of these children. “Ideally there should be a databank to keep track of all abandoned HIV-positive children,” said Voronin. “Now it’s as if they don’t exist. But the city administrations will be against this, because no one wants to shine a light on the actual conditions in which these children live.”⁹⁶

D) Longer-Term Effects of Isolation

In cases of orphaned children who test HIV-negative at eighteen months, they are then sent from the hospital to a regular baby house for healthy children. However, the psychological and developmental delays caused by a hospital existence may mark the child for life. Within the Russian orphanage system, a child stays in a baby house until the age of three or four years. After that those considered educable are sent to a regular

⁹⁴ Human Rights Watch interview, Voronin, Ust Yezhor, March 25, 2004.

⁹⁵ Ibid.

⁹⁶ Ibid.

orphanage; those who are mentally disabled are sent to an institution for the mentally disabled, the perils of which Human Rights Watch exposed in a 1998 publication. Children transferred to such institutions are deemed “ineducable” and deprived of the right to an education and many fundamental human rights.⁹⁷ Many of the children who are classified as HIV-negative but suffer from developmental delays as a result of an extended hospital stay often do not have the opportunity to catch up in time for them to be classified as “educable,” and therefore may be sent to an institution for the mentally disabled. The eighteen-month holding pattern when a baby is awaiting a diagnosis may end up being a life sentence of mental delay and neglect for an otherwise healthy child. “The hospital is no place for a small child. It is just not set up to deal with their needs. In a best case scenario you have forty children and three nurses. What kind of development for a child can there be in such an environment? They [the nurses] barely get to feed and change them,” said Viktor Kreidich, director of the Moscow baby house for HIV-positive children. “With no opportunity for development they all suffer from seriously delayed development. The longer the child stays in the hospital, the worse it is for his future psychological development.”⁹⁸

The numbers of these children may still be relatively small, but the problem is not going away in spite of the health and education ministries’ best efforts to ignore it. Russia will continue to see a rapid rise in the number of HIV-positive women giving birth. If the conditions for people living with HIV/AIDS in Russia remain unchanged—if drug users are denied access to substance abuse treatment, if HIV-positive women have no means of securing their legal rights to medical care and employment, if society continues to remain in frightened confusion about HIV/AIDS, and if the Russian government does nothing to secure the rights of HIV-positive women and ensure their children will have equal access to health care and education—then the numbers of children abandoned at birth will also rise. A greater effort must be made at the federal and local level to train employees and launch a public awareness campaign that aims to reshape society’s views of the virus’ most innocent victims.

III: HIV-Positive Families and the Problems Children Face

While HIV-positive women may face many obstacles during pregnancy, their challenges are multiplied with the birth of their children. It is only then they realize how limited their child’s world may be.

⁹⁷ Human Rights Watch, *Abandoned to the State: Cruelty and Neglect in Russian Orphanages* (New York: Human Rights Watch, 1998.)

⁹⁸ Human Rights Watch interview, Kreidich, Moscow, March 27.

Society's reaction to people living with HIV is so negative that parents try to hide the diagnosis. This is often impossible, especially in small towns where word of someone's HIV status can spread quickly. Their own position in society is so vulnerable that these parents often do not feel they are in a position to publicly reveal their status and stand up for their rights or the rights of their child.

One of the biggest problems they face is finding a *detsky sad* (daycare center or kindergarten) that will take their child. Irina Annagurbanova, director of a support center for HIV-positive families in St. Petersburg run by Innovations, a non-governmental organization, told Human Rights Watch: "No one is ready to take these children in [to kindergarten]. We had one case of a child who went for two weeks, but then the kindergarten director called the parents and asked them to take him home." The director may have been willing to take the child, but once the other parents found out there was an HIV-positive child at the kindergarten they put pressure on the school to have him expelled.⁹⁹

Preventing children from attending kindergarten or other educational facilities based on the medical status of the child and/or his parents is a violation of a number of international human rights standards enshrined in the Universal Declaration of Human Rights, the International Convention on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination Against Women, and the Convention on the Rights of the Child. The Committee on the Rights of the Child has affirmed that states must "ensure that primary education is available to all children, whether infected, orphaned or otherwise affected by HIV/AIDS."¹⁰⁰

Ironically, the discrimination they face at kindergartens throughout the city was prompting some HIV-positive families to consider a different form of discrimination, and one with a more lasting effect—segregation. Rather than fight their way into a school where they are unwanted, some HIV-positive families expressed a preference for segregated kindergartens for their own children. "We would prefer to send our daughter to a kindergarten for children of HIV-positive parents," said Alexei P.. "Society is just not ready [for these children], and I don't want my four- or five-year-old daughter to be subject to nasty comments from other children or their parents."¹⁰¹ Even when the child is not HIV-positive, the mere fact that the parent has the virus may be enough to fuel the fears of the community.

⁹⁹ Human Rights Watch telephone interview, Annagurbanova, St. Petersburg, April 1, 2004.

¹⁰⁰ Committee on the Rights of the Child, "General Comment 3: HIV/AIDS and the Rights of the Child," paragraph 18.

¹⁰¹ Human Rights Watch telephone interview, "Alexei P." St. Petersburg, June 7, 2004.

Russian law prohibits schools and kindergartens from rejecting a child because he is HIV-positive, but some families may not be up for the legal battle. “We try to speak to them about their rights, but many of our families are in a difficult position—some on the brink of poverty,” said Annagurbanova.¹⁰² For single mothers or low-income couples, finding a daycare that will take the child while the parents are working may be the difference between being able to keep the child at home or eventually perhaps seeking foster care or giving up the child to a government institution.

It is not at all certain that a child who goes home from the maternity hospital will not end up as a ward of the state sometime thereafter. While most abandoned HIV-positive orphans reportedly experience abandonment at birth, another trend appears to be emerging: delayed abandonment. In these cases, the child is abandoned some time after birth – sometimes after living several months within the family. Causes for this form of abandonment are varied. In some cases, the mother dies and a relative is not available to care for the child. In other cases, the relative who was caring for the child (in the absence of the mother) may be unable or unwilling to continue. The lack of a support network for HIV-positive families may thus be a major determinant in these cases. Often faced with problems of access to pediatric health care or getting the child into day care, parents may be unable to keep the child at home. Their burden may increase considerably in smaller towns where gossip spreads quickly and the stigma of their disease may render them as outcasts.¹⁰³

“We would like to send our girl to kindergarten, but you have to show your medical records there, so we can’t,” said Elena P., who was helping her daughter, a single HIV-positive mother, raise her granddaughter, now nearly four. “The kindergarten is right by our house, and we don’t want the neighbors to find out she is HIV-positive. It’s not that I expect them to throw rotten tomatoes at us, but it is psychologically unpleasant for me if they know. And that’s just the way I feel. What about how the baby will feel if they know she is HIV-positive? I don’t want to experiment on my own child. For us, anonymity is our biggest problem.”¹⁰⁴

While she did not complain of rudeness or discrimination at her local clinic, she worried about keeping her granddaughter’s diagnosis secret every time she took her to see a doctor. “Right there on the cover of her medical card it is written in capital letters: ‘She is sick with HIV.’ It’s written in big letters so that anyone standing a little off to the side

¹⁰² Human Rights Watch telephone interview, Annagurbanova, St. Petersburg, April 1, 2004.

¹⁰³ Human Rights Watch telephone interviews with Annagurbanova and Zagainova.

¹⁰⁴ Human Rights Watch telephone interview with Elena P., St. Petersburg, June 15, 2004. Human Rights Watch changed her name to protect her anonymity.

can see it,” said Elena P. “It appears like a warning: ‘Watch out! This is no simple child.’”¹⁰⁵

Kindergarten may be an immediate problem, but it is certainly not the only one. Access to certain public facilities that require a health certificate—such as swimming pools—are often off-limits.¹⁰⁶ As a result, parents may try to keep their child in a type of cocoon—as protected from the outside world as possible—to avoid unnecessary glares or confrontations.

“We worried more when my wife was pregnant, but now I see that the problems begin after the birth,” said Alexei P., whose daughter was born in February, 2004. Alexei P. and his wife educated themselves about MTCT and did everything they could to ensure their daughter would be born healthy. But they were not expecting the local pediatrician conducting at-home follow-up visits—a regular practice for all newborns in Russia—to be so contemptuous of them as parents. “She says that since we use narcotics we can’t look properly after the baby,” said Alexei P. adding that he and his wife have not used drugs in three years. “She said, ‘In any case you will not be able to turn drugs down at some point.’”¹⁰⁷ The local doctors also revealed a complete lack of understanding of HIV/AIDS and how it is transmitted, said Alexei P.. “They told us not to kiss our child and to keep a separate set of dishes.”¹⁰⁸

Shortly after their baby was born, Alexei P. and his wife stopped taking their daughter to the local clinic, opting instead to visit the pediatric specialist at the St. Petersburg AIDS Center. “My wife said, ‘No more. I’m not going back there [to the clinic] where they curse at us,’” said Alexei P.. The AIDS center was far from their home, but the long trip was worth it to both Alexei P. and his wife. And soon, he said, it would be worth it to his little girl. “Right now she is little so she doesn’t understand, but when she gets bigger she will feel the difference in how she is treated [from other children]. I don’t want her to be exposed to such treatment.”¹⁰⁹

¹⁰⁵ Ibid.

¹⁰⁶ Human Rights Watch telephone interview, Annagurbanova, St. Petersburg, April 1, 2004.

¹⁰⁷ Human Rights Watch interview, “Alexei P.,” St. Petersburg, March 18, 2004.

¹⁰⁸ Ibid.

¹⁰⁹ Human Rights Watch telephone interview, “Alexei P.,” St. Petersburg, June 7, 2004.

Conclusion

Taking visitors on a tour of St Petersburg's Baby House no. 10 last March, chief doctor Olga Kim fondly passed through wards of smiling children playing with their caregivers. Dr. Kim knows each of her 35 wards by name, stopping to issue kind words and caresses to many of them.

"Isn't it cozy here?" Dr. Kim says with motherly composure.

Baby House no. 10 is, in fact, about as cozy as a state institution can be. The children under Dr. Kim's care had the good fortune of securing one of thirty-five places in an orphanage where the staff is commendably affectionate and interactive with the children. But the very existence of Baby House no. 10 casts a dark cloud on the future of other abandoned victims of MTCT. The establishment of a segregated system of orphanages only fuels the fears of society, reinforcing the idea that these children are a danger and they must be isolated. Furthermore, the number of children being born cannot keep pace with the number of beds at such specialized orphanages. Those who do not get in have nowhere to go; as a result they may be left in a barren hospital room for years on end with no opportunity to develop physically and mentally.

With a few exceptions, Dr. Kim says that almost all of the children under her care were abandoned by mothers who are dependent on drugs. And as long as Russian health officials fail to increase access to drug rehabilitation and harm reduction programs to the country's four million drug users, Dr. Kim can expect that this problem will only get worse. There will be a longer and longer waiting list for the thirty-five beds in her orphanage.

Some believe that before Russia can win its battle against child abandonment, it has to give priority to the fight against drug addiction. But Russia needs to address more than drug treatment to battle the rising problem of mother-to-child-transmission. As HIV spreads from the high-risk groups to the general population, the percentage of "socially adapted" HIV-positive women with desired pregnancies will continue to rise. These women have a right to prenatal care that offers the greatest chances of giving birth to a healthy child. Russian health officials need to ensure that HIV-positive women have access to responsive medical care and accurate information about the available means of preventing transmission. They need unrestricted access to a short course of antiretroviral drugs; taken during pregnancy, this medication is known to significantly reduce the risk of transmission from mother to child. For those who are unwilling or unable to take this short course during pregnancy, hospitals must ensure that they have express HIV tests

and doses of nevirapine (for mother and child) during labor and delivery to reduce the risk of transmission.

Instead of being urged to have abortions or sent off with threats to the local AIDS Center, HIV-positive women need to be made welcome, their privacy guarded, their options discussed. In short, Russia needs to lift the stigma of HIV/AIDS in order to protect unborn generations from unnecessarily inheriting a deadly virus. In a society as large as Russia this is a difficult task, but starting with the medical community is a step in the right direction. When proper medication regimens can reduce the risk of transmission from 30 percent to less than five, the sorry consequences of negligent prenatal care are that much more apparent.

Finishing off her tour of Baby House no. 10, Dr. Kim expressed concern for the future of her wards: “Of course I am afraid for my children. I’m very afraid for their future, and how people will relate to them. These children are not dangerous to anyone. They can bring a lot of good to society. The most important question is that of adaptation. Society must adapt to our children and understand that they are valuable citizens. If they happened to experience tragedy, especially as children, then we should be that much more tolerant.”¹¹⁰

¹¹⁰ Human Rights Watch interview Kim, St. Petersburg, March 18, 2004.

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