

Abandoned Children Born to HIV-positive Women: Analysis of the Situation in Russia



**TRANSATLANTIC PARTNERS
AGAINST AIDS**

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Children Born to HIV–Infected Women and Child Abandonment:

ANALYSIS OF THE SITUATION IN RUSSIA

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Introduction

By the end of 2003, more than 13,000 children had been born to HIV-infected women in Russia; over 90% were born in just the last four years (2000-2003). By the end of 2004, the total may reach 20,000. And for at least the next several years, the number of children perinatally exposed to HIV-infection each year is likely to continue to grow, as a result of:

- continued growth in the number of HIV-infected women, most of whom are of childbearing age; and
- a probable increase in fertility among HIV-infected women, due to improved access to chemoprophylaxis (the use of antiretroviral drugs to prevent the perinatal transmission of HIV-infection) and perhaps to a reduction in the stigmatization of persons living with HIV/AIDS.

Although reality will inevitably diverge from today's forecasts, by end of the decade there could be as many as 8,000-10,000 cases a year in Russia of perinatal exposure to HIV-infection.

Of all children born to HIV-infected women by the end of 2003, an estimated 15%-20%, roughly 2,000-2,500 in all, were (are) HIV-infected themselves. Some of these children-perhaps as few as 10%, according to some experts-need specialized treatment in the first few months after birth. But all of them, sooner or later, will need combination antiretroviral therapy in order to remain healthy. If the rate of mother-to-child transmission of HIV-infection is not lowered, there may soon be as many as 2,000 new cases of perinatal HIV-infection annually. Fortunately, the transmission rate can be reduced to as low as 5% relatively easily, by increasing the number of HIV-infected pregnant women who receive prenatal care and by improving their access to antiretroviral prophylaxis.

Children born to HIV-infected women are many times more likely to be abandoned than children born to uninfected women. Approximately 10% of all perinatally exposed children in Russia born prior to the end of 2003, perhaps 1,300 children, have been left to the care of the state-either officially relinquished or abandoned *de facto* in state institutions. Many of these children have been forced to spend the first months, or even years, of their lives in hospitals, suffering severe physical, intellectual, and emotional stunting that in some cases is now irreversible. All experts in the field of child development agree that the family-as compared to an institution-is by far the best place to raise a child. Yet, only a few of these abandoned children have been adopted or placed in one or another form of foster care. There are several reasons for the prolonged hospital stays and infrequent family placements of these children. By far the most important is the unjustifiably long time it takes to establish a perinatally exposed child's HIV-status. In the vast majority of cases, children born to HIV-infected women in the Russian Federation are not diagnosed officially before they are 18 months old, even though contemporary medicine makes it possible to do this within the first 3-6 months of a child's life.

This report is focused on children who have been perinatally exposed to HIV-infection and then abandoned by their parents to the care of the state. The main objective of our work is to present information about the current situation in Russia to those political leaders and healthcare experts who are committed to improving the effectiveness of measures aimed at preventing the transmission of HIV-infection from mother to child and to reducing the level of child abandonment in the Russian Federation. In this respect our report has two, more specific goals: 1) to examine the main causes of abandonment of children born to HIV-infected women and to develop recommendations aimed at preventing or reducing it; and 2) to examine the consequences of child abandonment and to identify measures needed to improve the living conditions of these children and to ensure they have the future they deserve.

Our report is divided into five chapters:

- Chapter One presents estimates of the amount of abandonment among children born to HIV-infected women and examines several steps taken by the Russian government in order to improve epidemiological surveillance of various aspects of perinatal HIV-infection.
- Chapter Two examines possible causes of child abandonment by HIV-infected mothers. Special attention is directed at the linkage between prenatal care and child abandonment, as well as at factors that might prompt a mother to decide to abandon her child following delivery.
- Chapter Three focuses on the fate of abandoned children born to HIV-infected women. Here we examine the reasons behind their prolonged hospital stays and the infrequency with which they are placed in "substitute families." We also consider the readiness of children's homes (*detskiye doma*) to accept the rapidly growing cohort of abandoned children who should be transferred out of infant homes (*doma rebyenka*) once they reach the age of three. And we analyze the continuing risk of abandonment experienced by many of the children who have been kept by their mothers, due to their families' very difficult social and economic circumstances.

- Chapter Four offers a brief survey of experience in the United States with respect to two issues that may be of interest to Russian policymakers. We describe several measures adopted by the American government in response to a sudden upsurge in child abandonment that occurred in the mid-1980s, caused by the confluence of rapidly spreading epidemics of HIV-infection and illegal drug use. We also examine actions aimed at lessening the rate of mother-to-child transmission of HIV-infection.
- Chapter Five summarizes the main findings of the preceding chapters and proposes a number of steps that the Russian Government might consider taking in order to reduce the amount of child abandonment and to improve the lives of all children born to HIV-infected women.

This report is based on a wide array of sources, including: existing legislative acts; relevant decrees issued by the Russian Government (and by the Russian Ministry of Health and Social Development and other state agencies in particular); and various publications, including statistical compendia, monographs, and articles in journals and newspapers. The report also has utilized the following:

- a detailed analysis of perinatal HIV infection in Russia, presented by the Russian Ministry of Health and Social Development to an information-and-discussion meeting of the Interfactual Deputies' Working Group on the Prevention of HIV/AIDS, which was held July 1, 2004 [23];
- a report on research in 10 regions of the Russian Federation, concerning all major aspects of mother-to-child transmission of HIV-infection (as of mid-2003), that was conducted by Russian experts and supported by the Russian Ministry of Health and Social Development and by UNICEF [21]¹ — here after, referred to as the UNICEF Report; and
- statistical data on the number of children born to HIV-infected women, provided by the Federal Applied Research Center for the Prevention of and Fight Against AIDS (hereafter, the Federal AIDS Center).

In addition, *Transatlantic Partners Against AIDS* (TPAA) conducted its own independent research for the purpose of collecting information, in which connection TPAA staff visited a number of healthcare facilities, social assistance centers, infant homes, and other institutions in Moscow city, Moscow Region, and the cities of St. Petersburg and Irkutsk. The following research methods also were employed:

- statistical data on perinatal exposure to HIV-infection and child abandonment were collected from five regions not covered in the UNICEF Report;
- 24 interviews were conducted, some by telephone, with staff members from regional AIDS centers, infant homes, and non-government organizations serving families affected by the HIV/AIDS epidemic; and an additional 18 interviews were conducted with parents and other relatives of perinatally-exposed children, including several mothers who had abandoned a child.

This report was made possible thanks to invaluable contributions received from many specialists on issues relating to HIV/AIDS and the medical and social problems of maternity and childhood, as well as from the representatives of civic organizations and communities of persons living with HIV/AIDS. Transatlantic Partners Against AIDS (TPAA) expresses its profound gratitude to the following persons for their assistance and expert support: O.V. Sharapova, L.V. Pospelova, and V.N. Sadovnikova (Russian Ministry of Health and Social Development); G.N. Trostanetskaya, A.A. Gerish, and M.P. Kotel'nikova (Russian Ministry of Education and Science); Ye.Ye. Voronin (Applied Research Center for the Prevention and Treatment of HIV-Infection in Pregnant Women and Children); A.I. Mazus (Moscow City AIDS Center); N.V. Gorshkova (Volgograd Regional AIDS Center); L.V. Sultanov and E.R. Dem'yanenko (Altay Territorial AIDS Center); L.A. Ruzayeva (Krasnoyarsk Territorial AIDS Center); A.Yu. Pronin (Moscow Regional AIDS Center); I.E. Tadzhiyev (Astrakhan Regional AIDS Center); I.I. Ryumina ("Healthy Russia"); V.Yu. Kreydich (Children's Home No. 7, Moscow city); M.I. Narkevich (Russian Ministry of Health's Advisory Council on Problems of HIV-Infection & the not-for-profit organization "Medantispid"); A.G. Rakhmanova (St. Petersburg City Public Health Committee); Ye.N. Vinogradova and E.F. Senchik (St. Petersburg City AIDS Center); T. Yepoyan (UNICEF); Ye.V. Sokolova and M.R. Bobkova (Federal AIDS Center); A. Bobrik (Open Health Institute); T. Shumilina (UNAIDS); M.O. Dubrovskaya ("Aid to Russian Orphans"); G.A. Tyuleneva (Children's Infectious Disease Hospital No. 3, St. Petersburg); O.A. Kim (Infant Home No. 10, St. Petersburg); A. Tsekhanovich and A. Panov ("Humanitarian Action," St. Petersburg); I. Kuzmina ("Innovation Center," St. Petersburg); V. Musatov (Botkin Infectious Disease Hospital No. 30, St. Petersburg); N. Panchenko (HIV/AIDS information center, "Doverie"); O. Sedurina (TV-Radio Company, "Avtoradio TV," Perm'); S. Hillis (Centers for Disease Control and Prevention); T. Monk (Holt International); J. Dickson and D. Postnov (AIDS Foundation East-West).

¹ A descriptive and analytic review, *Deti, zhenshchiny i VICH-infektsiya* (Children, Women and HIV-Infection) was subsequently published on the basis of this report [8].

Chapter 1. The Epidemiological Surveillance of Children Born to HIV-Infected Women

This chapter has three goals. The first is to analyze the available empirical data concerning perinatal aspects of the spread of HIV-infection, including the number of children born to HIV-infected women and the number of abandoned children. A second goal is to analyze measures adopted by the Federal Ministry of Health and Social Development of the Russian Federation, aimed at improving the epidemiological surveillance and reporting of mother-to-child transmission (MTCT) of HIV-infection. The third goal is to suggest a few steps that might contribute to the further improvement of epidemiological surveillance in this field. The ultimate purpose of the measures we propose is: 1) to broaden and deepen the analysis of the current situation in Russia concerning all aspects of the lives of children born to HIV-infected women; (2) to improve the quality of forecasting; and (3) to spur the adoption of more effective policies designed to prevent child abandonment.

I. Estimates of the Number of Children Perinatally Exposed to HIV-Infection

Different estimates have been made of the number of children born to HIV-infected women in Russia since the start of the epidemic. In July 2004, at an expanded meeting of the Interfactual Deputies' Working Group on the Prevention of HIV/AIDS, which was devoted to the problems of children who have been perinatally exposed to HIV-infection and then abandoned, the Russian Ministry of Health and Social Development presented data on the number of **births** (not children born) by HIV-infected women in obstetric hospitals during the period, 2000-2003, and also on the number of children who were abandoned by their mother following delivery (Table 1.1). On the basis of these data and additional information provided by the Ministry of Health, it is estimated that a total of 12,660 **children** were born to HIV-infected women during this four-year span.² This is likely the most reliable estimate available, although it exceeds by a significant amount the estimate offered (privately) by the Federal AIDS Center which reports a total of 8,594 children born to HIV-infected women in 2000-2003 (Table 1.2).

Table 1.1
Numbers of births and abandoned children by HIV-infected women in obstetric hospitals, Russian Federation, 2000-2003

	2000	2001	2002	2003	Total, 2000-2003
Number of births by HIV-infected women*	668	1,939	4,523	5,823	12,953
Number of abandoned children born to HIV-infected women	75	157	262	275	769
as % of all children born to HIV-infected women	11.4%	8.2%	6.0%	4.8%	—

Source: [23]

Note:

* The number of births is not equal to the number of children born, on account of multiple and still births. The total number of live children born to HIV-infected women, calculated on the basis of unpublished data supplied by the Russian Ministry of Health, was slightly smaller than the number of births: 656 in 2000, 1,911 in 2001, 4,365 in 2002, and 5,728 in 2003. Thus, the total number of children born to HIV-infected women in 2000-2003 was 12,660 (97.7% of the number of births); 6.1% of these children were abandoned.

² After the Russian version of this report was completed, the authors obtained a copy of an Informational Circular, "On Pregnancies and Births by HIV-Infected Women in the Russian Federation," dated 15 September 2004, issued by the Federal Ministry of Health and Social Development and intended for staff in the gynecological, obstetric, and pediatric services. In the Circular, it is explained that, beginning in 2000, standard obstetric facility reporting (Form №. 32) was changed so facilities began to report separately the total number of births by HIV-infected women, as well as additional information about these births, including cases of abandonment [2:4]. This enhanced reporting is the source of the ministry data presented in Tables 1.1 and 1.2.

Table 1.2**Different estimates of the number of children born to HIV-infected women, Russian Federation, 2000–2003**

	2000	2001	2002	2003	Total, 2000–2003
Number of children born to HIV-infected women:					
• according to data from the Ministry of Health*	656	1,911	4,365	5,728	12,660
• according to data from the Federal AIDS Center	602	1,475	3,173	3,344	8,594
Federal AIDS Center estimate as % of Ministry of Health estimate	92%	77%	73%	58%	68%

Sources: [23]; Federal AIDS Center.

Note:

* Figures in this row are calculated on the basis of data provided by the Russian Ministry of Health. See the note to Table 1.1 for an explanation.

Several months before the meeting of the Interfactual Deputies Group, in June–November 2003, experts from the Russian Ministry of Health's Applied Research Center for the Prevention and Treatment of HIV-Infection in Pregnant Women and Children, a division of the Republic Clinical Infectious Diseases Hospital (RKIB) outside St. Petersburg, undertook a major research project on issues relating to the prevention of MTCT, the provision of medical care and social assistance to mothers and children, and the assurance of conditions needed for the full development of children born to HIV-infected women [21]. Supported by the Russian Ministry of Health and by UNICEF, this study consisted mainly of fieldwork conducted in 10 regions of the Russian Federation, all characterized by high adult prevalence levels of HIV-infection and by large numbers of children born to HIV-infected women. The 10 regions covered by the study included: Irkutsk, Kaliningrad, Leningrad, Moscow, Orenburg, Samara, Sverdlovsk and Chelyabinsk regions, as well as the Tatarstan republic and St. Petersburg. These ten regions combined probably accounted for between 50–60% of all children born to HIV-infected women in Russia at the time the research was conducted. According to data collected for this study, approximately 5,200 children were born to HIV-infected women in these regions between the start of the HIV epidemic (1987) and the middle of 2003. This figure also is significantly higher than the number reported (privately) for these 10 regions by the Federal AIDS Center (Table 1.3). Data obtained directly from several additional regions (i.e. not covered by the UNICEF Report) during the preparation of the present report likewise diverge from figures reported by the Federal AIDS Center.³

Despite the differences in scope and time periods covered, the estimates of the number of children born to HIV-infected women presented by the Ministry of Health and collected by the authors of the UNICEF Report are generally consistent with one another. Both estimates suggest that by the end of 2003, approximately 13,000–14,000 children had been born to HIV-infected women in the Russian Federation.⁴

As for the number of abandoned children, according to data from the Ministry of Health, 769 (6.1%) of the children born to HIV-infected women during the period, 2000–2003, were relinquished by their mothers at the maternity hospital. In fact, a much larger number of children have ended up bereft of a parent's care, for the risk of abandonment does not end when the new mother and her infant are discharged and sent home.

Unfortunately, it would be an extremely labor-intensive and time-consuming task to determine a more accurate estimate of the total number of children born to HIV-infected women who have been abandoned. Doubtless one of the most reliable methods of collecting such information would be intensive fieldwork of the sort conducted by the authors of the UNICEF Report. The latter found that children whose parents either relinquished their parental rights, formally or *de facto*, or were deprived of their rights, constituted over 10%

³ For example, the Federal AIDS Center reported a total of 10 children born to HIV-infected women in Perm' Region as of mid-2004; but according to information provided by the region, there were more than 300 such children. Similarly, for Volgograd Region, the Federal AIDS Center reported 11 children born to HIV-infected women by the end of 2003; information from the region put the number at 160.

⁴ If one assumes (i) that the total number of perinatally exposed children in the 10 regions combined at the time data collection ended (March–June 2003) was between two-thirds and three-fourths of the number at the end of 2003 and (ii) that the 10 regions together at the time accounted for between 50%–60% of all perinatally exposed children in Russia, then the data collected for the UNICEF Report imply a total for all of Russia of between 11,500–15,500 perinatally exposed children as of the end of 2003.

(N=542) of the 5,115 children born to HIV-infected women who were still living in the ten regions investigated for the UNICEF Report (Table 1.3). Data obtained independently from several other regions likewise suggest that roughly 10% of children born to HIV-infected women, on average, sooner or later end up as wards of the state. Thus, in Krasnoyarsk Territory, as of July 2004, 37 of the 390 children known to have been born to HIV-infected women had been abandoned. This number included 22 children who had been formally relinquished by their mothers at birth, 10 children who were abandoned at the maternity hospital without a formal declaration of relinquishment, three children who had been left by their mothers "temporarily," and two whose mothers had been deprived of their parental rights.⁵ Based on all available data, it is estimated that approximately 1,300–1,400 children of those born to HIV-infected women by the end of 2003 have been abandoned.

Table 1.3

Different estimates of the number of children born to HIV-infected women in 10 regions, 1987-early 2003

Category	Irkutsk region	Kaliningrad region	Leningrad region	Moscow region	Orenburg region	Samara region	Sverdlovsk region	St. Petersburg	Tatarstan republic	Chelyabinsk region	Total
(1) No. children born to HIV-infected women (UNICEF Report)	687	243	267	535	246	646	1,087	997	170	342	5,220
(2) No. children born to HIV-infected women (Federal AIDS Center)	660	222	93	512	200	660	804	564	40	258	4,013
Federal AIDS Center estimate as % of UNICEF Report estimate: (2) as % of (1)	96%	91%	35%	96%	81%	102%	74%	57%	24%	75%	77%
(3) as % of (1)*	76	42	27	37	14	61	57	176	15	37	542
(3) as % of (1)	11	17	10	7	6	9	5	18	9	11	10.4

Source: [21]; Federal AIDS Center.

Note:

* Data are for the following time periods:

Irkutsk, Leningrad, Orenburg, Samara, Sverdlovsk & Chelyabinsk regions: 1987 – 01 April 2003;

Moscow region: 1998–2002;

Kaliningrad region and Tatarstan: 1987 – 01 July 2003;

St. Petersburg: 1987 – 22 October 2003.

It should be noted, in this connection, that there is a state databank established by decree of the Russian government, covering all children who have been orphaned or abandoned. This databank does not have any direct connection to the epidemiological surveillance system; it was created in order to accelerate family placements of children left without parental supervision. But this databank, given technical modernization and better interagency cooperation, might in the future serve as a source of information about the children of interest to us here.⁶ For in principle, this databank contains information on the health status of each child, including the HIV-status of the child's mother; while Russian Ministry of Health Order No. 218, dated 08 July 2002, provides that all changes in the child's health status are to be entered at least once a year. However, technical capabilities of the databank do not permit automatic sorting of the data, based on the HIV-status of mother or child. Determining the actual number of children perinatally exposed to HIV-infection would have to be done manually, by scanning case records for hundreds of thousands of children. Moreover, children taken in by adoptive or foster families are dropped from the databank; as a result, information in the databank cannot be used for analyzing or forecasting future abandonment of perinatally exposed children.

⁵ Information provided by the Krasnoyarsk Territorial AIDS Center.

⁶ For research purposes, it would be important to be able to use data that have been stripped of all personal identifying information.

II. Measures to Improve the Organization of Epidemiological Surveillance

Discrepancies in the estimates of the number of children born to HIV-infected women, described earlier, are one of the reasons why the Russian Ministry of Health adopted measures to improve standard case reporting of perinatal HIV-infection. In 2003-2004, two orders were issued establishing new reporting procedures. Russian Ministry of Health Order No. 442, dated 16 September 2003, introduced new forms for reporting (1) children born to HIV-infected women, (2) removal of a child's provisional diagnosis of HIV-infection (i.e. formal establishment of the child's HIV-negative status), and (3) confirmation of a child's provisional diagnosis (i.e. formal establishment of the child's HIV-positive status). The first of the new forms mandates that information be reported on chemoprophylaxis received by the mother and/or newborn infant, on whether (when) the mother was placed on the pregnancy registry, etc. The Order requires that, effective 01 January 2004, the new reports are to be submitted (by the obstetric hospital and/or facility responsible for ordering the HIV test) to the regional AIDS centers which, within three days of receiving them, are to forward the data to the Applied Research Center for the Prevention and Treatment of HIV-Infection in Pregnant Women and Children at the RKIB. Russian Ministry of Health Order No. 9, dated 19 January 2004, introduced yet another new reporting form, this one covering pregnancy outcomes (i.e. live and still births, as well as abortions) among HIV-infected women. Effective 01 February 2004, these data are to be submitted to the Research Center for Obstetrics, Gynecology, and Perinatology of the Russian Academy of Medical Sciences.

One of the positive aspects of the new reporting requirements is that official data on such things as the number of births by HIV-infected women, the number of children born, the number of cases of abandonment at birth, and the number of positive and negative diagnoses of perinatal HIV-infection ought to become more reliable. Matched data on mothers and children doubtless will make it possible to develop more detailed information on the prevalence of HIV-infection in pregnancy and the mechanisms of MTCT, as well as better assessments of the specific strategies used to prevent MTCT. In view of the RKIB's considerable clinical experience in treating HIV-infection in children, one can expect that the information generated by the new reporting requirements will contribute to the development of more effective strategies for preventing MTCT and for treating infected mothers and children.

Nevertheless, the forms and the procedures for distributing the information could both be improved. For example, the new case report is to be submitted within 10 days of the child's birth, that is, before certain chemoprophylaxis regimens have ended (e.g. the six-week course of zidovudine), which means that data on the administration of chemoprophylaxis will necessarily be incomplete. More seriously, information on breastfeeding will cover only the time period during which the mother and her infant are at the maternity hospital. In addition, there is no clear statement regarding the mechanisms of interaction and channels for exchanging information between the research centers, on the one hand, and the Federal AIDS Center, on the other. Good cooperation and the free exchange of information (between these institutions) are vital if there is to be high-quality epidemiological surveillance at the national level.

III. The Need for Additional Methods of Epidemiological Surveillance of HIV-Infection

A growing number of experts in the field of HIV/AIDS believe that so-called "first generation" methods of epidemiological surveillance, such as are used in the Russian Federation, need to be supplemented with "second generation" methods. First-generation methods are based on the reporting and enumeration of all detected cases of HIV-infection. Second-generation methods include: (a) targeted testing for the purpose of measuring disease prevalence among particular sub-groups in a population; and (b) behavioral studies, aimed at identifying the factors that determine the paths and frequency of transmission both within and across sub-groups and into the general population [22; 35]. For example, it is believed that a significant number of HIV-infected women who have abandoned their children are injection drug users (IDUs). But in order to better understand the linkages between injection drug use, the transmission of HIV-infection from mother-to-child, and child abandonment, one needs to know: the percentage of all injection drug users who are HIV-infected, the percentage of HIV-infected pregnant women who are also injection drug users, the fertility decisions of both HIV-infected and uninfected women who use drugs, and other characteristics of both categories of women (family status, education, employment, income, utilization of healthcare services, etc.)-and how these factors may be changing over time.

Although interest in these kinds of studies is growing, they still have not become an important part of the epidemiological surveillance of HIV-infection in the Russian Federation. One would hope that the findings of the present report will demonstrate to readers the need to support such research and to encourage those institutions responsible for the surveillance of HIV-infection to keep in mind the necessity of using "second generation" methods when preparing their reports and developing their forecasts.

Chapter 2. Women, HIV–Infection and Child Abandonment

This chapter has three goals: (1) to examine the empirical correlates of child abandonment by HIV-infected women; (2) to look for factors that may determine a woman's decision to abandon her child; and (3) to assess the steps that the government has taken in an effort to reduce the likelihood of abandonment among children who have been perinatally exposed to HIV-infection.

Child abandonment in general has become an acute problem in the Russian Federation. In recent years, approximately 5,500 children under a year old have been placed in infant homes (*doma rebyenka*) each year, roughly 0.4% of total births [1:112].⁷ Although some of these children are natural orphans, one or both of whose parents have died, most are so-called "social orphans," that is, children who have been officially relinquished to the state or abandoned in a hospital or elsewhere, or whose parents have been incarcerated or legally stripped of their parental rights. In practice, only a minority of "social orphans" end up in institutions; most are either adopted or taken in by an adult relative who becomes officially the child's guardian (*opekun*). A recent study in St. Petersburg for 2002 found that nearly one percent of all children born in the city that year ended up abandoned [31]. At the same time, as that study demonstrated and as shown by other data, HIV-infected women are significantly more likely to abandon their children than uninfected women. The data presented in Tables 1.1 and 1.3 in the last chapter suggest that as many as 10% of the children born to HIV-infected women become social orphans.

The greater frequency of child abandonment among HIV-infected women usually is explained by the large number of so-called "mal-adapted" women in this group, in particular, drug addicts. This view leads one to suppose that "social deviancy" might explain, at least to a certain degree, the abandonment of children, although there are no statistical data bolstering this conclusion: the research needed to determine the relationship between child abandonment and various social and behavioral factors has not yet been done.

Data obtained from two Russian regions during preparation of the present report showed no statistically significant relationships between abandonment and social factors, including drug use. Specifically, analysis of a random sample of 64 HIV-infected mothers living in Irkutsk Region showed that at the time of their child's birth, only half the women were married, two-thirds were unemployed, and nearly three-fourths had experience of drug use. But not one of these factors had a statistically significant association with the woman's decision to abandon her child (Table 2.1). It is possible that this result is due to the small sample size and that a larger study would find a relationship between child abandonment and social factors.

Table 2.1

Social characteristics of HIV-infected mothers and frequency of child abandonment, Irkutsk region, 1999–2004 (N=64)

	% of all women in the sample	% of the women who abandoned a child
unmarried (N=33)	52	36
unemployed (N=44)	69	41
past/current drug use (N=47)	73	40
Total sample (N=64)		39

Source: Irkutsk Regional AIDS Center

Note: Data in the table were derived from case records of a randomly selected sample of HIV-infected mothers, stratified by those who did and did not abandon a child (N=39, N=24).

⁷ Infant homes are state-run orphanages for children three years of age and younger, which are administered by the public healthcare system. After reaching the age of three, most children are transferred from infant homes to children's homes (*detskiye doma*) which are administered by the public school system. When the children are seven, they are generally transferred to boarding schools (*internatnyye uchebnyye zavedeniya*) which also are administered by the public school system.

I. Child Abandonment and Prenatal Care

A mother's decision to abandon her child can be predicted with a certain amount of confidence, based on whether or not she was placed on the pregnancy registry at her local women's health service. The strongest evidence of a link between child abandonment and enrollment for prenatal care was presented in the previously cited study in St. Petersburg that was conducted jointly by Russian and American experts and published in the British medical journal, *The Lancet* [31]. The researchers found that new mothers who were HIV-infected abandoned their children 10 times as often as uninfected mothers; and that HIV-infected women who were **not on the pregnancy registry** were 7.5 times more likely to abandon their children than HIV-infected women who **were on the registry**. In all, approximately a fourth of the HIV-infected women who gave birth in St. Petersburg in 2002 did not receive prenatal care (compared to less than 4% of uninfected women). Yet, these women accounted for 70% of all perinatally exposed children who were subsequently abandoned (Table 2.2).

The authors of the UNICEF study likewise report that among pregnant women who are examined regularly by an obstetrician-gynecologist during pregnancy, "there are as a rule no instances of child abandonment." The authors continue: "Children are abandoned by asocial women who use drugs, or who are not examined during their pregnancy at the women's health service or at the AIDS center, and also in cases when the pregnancy was unwanted" [21; also, see 8:53]. The researchers found that in 9 of the 10 regions for which they had good data, a sixth of all HIV-infected women, on average, were not on the pregnancy registry [and thus not enrolled for prenatal care] prior to their presenting at the maternity hospital for delivery (Table 2.3).

That so many HIV-infected women who become pregnant never register for prenatal care is hardly surprising. Long-term drug use can suppress menstruation, and so some women who are drug-dependent may not realize they are pregnant until relatively late in their pregnancy, at which time registration for prenatal care may seem pointless. Women lacking a local residence permit or employer-provided health insurance may be turned away from healthcare facilities-or they may deliberately avoid those facilities in order *not* to attract the attention of local authorities. Other women may be treated so rudely by healthcare personnel that they become discouraged and want nothing to do with the facility. In an interview, a young mother of two recalled: "The gynecologist's attitude was such that you didn't want to go there, sometimes you would cry before going there. When I was pregnant the second time, only at 8 months did I go to register my pregnancy [with the women's health service]. I went to the AIDS center early and received [prophylactic] treatment, but I didn't go to [the women's health service], there it was only stress. They began to scold me, why did I come so late. But why go to them? They look at you like you're the walking plague."

Nevertheless, the vital importance of prenatal care-for reducing the likelihood of perinatal HIV-infection and, ultimately, for reducing child abandonment by HIV-infected mothers-would seem to be self-evident. For the pregnant woman who does not know she is infected, prenatal care can provide a pretext and opportunity to be tested. In the UNICEF study, researchers found that, depending on the region, between 12%-38% of all HIV-infected mothers did not learn their HIV status until after arriving at the maternity hospital [21]. On the other hand, for the pregnant woman who already knows she is infected, the information she receives regarding the likelihood of her child becoming infected, as well as the consequences should transmission occur, can help her not only to make a more careful and considered decision as to whether to continue the pregnancy, but also, should she choose to bear her child, to prepare herself for the future.

Table 2.2
HIV-status, prenatal care, and child abandonment in St. Petersburg, 2002

	uninfected	HIV-infected
Of all women who gave birth in 2002:	(N=38,621)	(N=485)
not on the pregnancy registry, %	3.5	23.5
abandoned her child, %	0.9	8.9
Of women on the pregnancy registry:		
abandoned her child, %	n.d.	3.5
Of women not on the pregnancy registry:		
abandoned her child, %	n.d.	26.3

Source: [31].

Note: n.d. = no data

Table 2.3

Child abandonment, prenatal care, premature termination of pregnancy and chemoprophylaxis coverage during pregnancy, 10 regions, 1987 — early 2003

Region	(1) abandoned children, %	(2) women <i>not</i> on pregnancy registry, %	(3) prematurely terminated pregnancies, %	(4) received chemoprophylaxis during pregnancy, %
Irkutsk region	11.3	26.3	46.9	34.9
Kaliningrad region	18.3	41.8	70.3	51.1
Leningrad region	10.3%	10.5	48.4	64.4
Moscow region	6.9	12.3	47.9	63.7
Orenburg region	5.7	24.4	46.4	42.3
Samara region	9.7	19.0	55.7	35.4
Sverdlovsk region	5.4%	7.1	43.4	2.7
St. Petersburg	18.0%	n.d.	33.3	53.6
Tatarstan	8.8%	0	64.7	n.d.
Chelyabinsk region	11.1	19.5	71.1	33.4
Total				
average, %	10.6	16.5	50.9	37.3
Correlation matrix:*				
(1) abandoned children, %	1.000	0.699	0.142	0.372
(2) not on pregnancy registry, %		1.000	0.286	0.192
(3) prematurely terminated pregnancies, %			1.000	-0.017
(4) ARV prophylaxis during pregnancy, %				1.000

Source: [21].

Notes:

- (1) number of abandoned children born to HIV-infected women/number of children born to HIV-infected women still living in region for whom there are data;
- (2) number of HIV-infected women who were not on pregnancy registry at time they gave birth;
- (3) (number of HIV-infected pregnant women — number who gave birth)/number of HIV-infected women;
- (4) number of HIV-infected women who received chemoprophylaxis during pregnancy/number of HIV-infected women who gave birth.

* Statistics are Pearson r correlations. The correlation ($r=0.699$) between percent abandonment (1) and percent not on the pregnancy registry (2) is significant ($F=6.69$) at $p < 0.05$.

n.d. = no data

Prenatal care early in pregnancy can help to lessen the perinatal effects of HIV-infection on the child and also to lower the risk of abandonment by (1) reducing the number of unwanted pregnancies and (2) lowering the risk, as well as the emotional costs, of the birth of an HIV-infected child.

The negative attitude shown by society (and often by healthcare workers) pushes many pregnant HIV-infected women to end their pregnancies prematurely. Ye. V. Sokolova, senior researcher at the Federal AIDS Center, reports that in a written survey of obstetrician-gynecologists, a majority of respondents (68%) regarded pregnancy as undesirable for HIV-infected women. Indeed, 16% of the surveyed physicians advocated "artificial termination of the pregnancy in any instance," that is, regardless of the woman's somatic, psychological, or socio-economic condition and/or other indications for terminating the pregnancy [16]. The prejudice shown by healthcare workers toward HIV-infected women has been described in numerous newspaper articles [e.g. 14] and was mentioned often in interviews conducted during the preparation of this report. On the other hand, according to some experts, fertility among HIV-infected women is significantly lower than among uninfected women, possibly because of the relatively greater use of barrier contraception to prevent heterosexual transmission between partners [16]. In theory, both of these factors—pressure from society to abort, plus lowered fertility—ought to mean, all other things equal, that a higher percentage of pregnancies brought to term by HIV-infected women are desired, as compared to pregnancies brought to term by uninfected women.

Empirically, it is difficult to distinguish these effects, since, in the first instance, they work in opposite directions: pressure on the woman should increase the abortion rate, while lower fertility should reduce it. In fact, according to available data, HIV-infected women on average terminate their pregnancies less frequently than uninfected women, even though the abortion rate nationally has fallen sharply in recent years. Thus, in 2002 there were 139 abortions per 100 births among all women in Russia [1:101], while in 2003 the figure was 117 abortions/100 births [2:10]. In the regions investigated for the UNICEF Report, the abortion rate among HIV-infected pregnant women [for the period 1987-mid-2003] was approximately 1:1 (Table 2.3). In 2003, according to the Russian Ministry of Health and Social Development, the national abortion rate among HIV-pregnant women was 64 abortions/100 births [2:10].

The implication of these data is that most of the HIV-infected women who register for prenatal care and bring their pregnancy to term must enter the maternity hospital, wanting and **expecting** to keep their child. The data also imply (but do not prove) that a sizable portion of those HIV-infected women who do not receive prenatal care—variously estimated to constitute 15%-25% of all births by HIV-infected mothers—probably would have terminated their pregnancy, had there been a suitable opportunity to do so. It is likely that these women are responsible for the majority of abandoned children who have been perinatally exposed to HIV-infection.

II. Preventing Abandonment After Birth

Many HIV-infected mothers who subsequently abandon their children may arrive at the maternity hospital, having already made their decision. But evidently not all do so. Although there are no statistical data demonstrating this, interviews with HIV-infected mothers suggest that some women who end up abandoning their children are initially undecided about whether to keep their babies, and that some even go into labor, fully expecting to take their children home with them. For these women, events or calculations occurring during or after delivery must somehow "tip the balance" between retention and abandonment. Such factors may include: the relative health of the new-born infant and how this is likely to affect the child's future development; and the amount of support and encouragement received from physicians, staff, and other patients during the mother's hospital stay. For a few mothers, the key factor may be the immediate stress created by the sudden cessation of drug use (and the onset of drug withdrawal); for others, it may be the belated realization that, with too little money and/or social support, she and her family are likely to be overwhelmed by the needs of another child.

Table 2.4
Transmission of HIV-infection from-mother-to-child, 10 regions, 1987-early 2003

	Total	% confirmed to be HIV-infected
No. children born to HIV-infected women	5,115	2.9
of whom: no. of abandoned children	542	15.3

Source: [21]. See Table 1.3 for a list of regions and time periods covered.

Table 2.5

Health status of newborn infants perinatally exposed to HIV-infection, grouped into those who were later abandoned and those who were not abandoned (data from the RKIB)

	Children who were abandoned (N=69), %	Children who were <i>not</i> abandoned (N=41), %
Gestational age (weeks)		
≥ 38	38	93
32–37	53	7
≤ 31	9	—
Birth weight (grams)		
≥ 3 000	20	62
2 000–2 999	32	38
≤ 1 900	48	—
Apgar score 1 min after birth (0-10)		
8–9	17	86
6–7	77	14
≤ 5	6	—

Source: [20].

a) The Infant's Health Status

Children born to HIV-infected women who are then abandoned are themselves infected with the virus much more frequently than children who are not abandoned. In the ten regions surveyed for the UNICEF study, more than 15% of abandoned children born to HIV-infected mothers [that is, among children whose diagnosis had been established officially] were HIV-infected, compared to less than 3% of **all** children with an established diagnosis (Table 2.4)⁸. It also appears that abandoned infants, **irrespective** of whether or not they become infected, are born in poorer health. The Center for the Prevention and Treatment of HIV-Infection in Pregnant Women and Children has found that perinatally exposed infants who are subsequently abandoned tend to have lower gestational age, lower birth weight, and lower Apgar scores immediately after birth, compared to infants who are not abandoned (Table 2.5) [20].

These findings can be variously interpreted. On the one hand, it may be that those mothers who give birth, having already decided to relinquish their child, "invested" less in their babies during pregnancy, e.g. by not obtaining prenatal care and/or chemoprophylaxis, by continuing to use drugs or alcohol, by ignoring proper nutritional guidelines, etc. On the other hand, perhaps the abandoning mother, having given birth, recognizes the signs of her child's relatively worse health status and makes a "rational" decision to relinquish him or her in order to avoid the sizable emotional and financial burden likely to be associated with raising a weak and sickly child. Whatever the explanation, the evidence suggests that abandoned children are likely to require much greater care than children who are not abandoned, and that the comparatively poorer health status of children who are subsequently abandoned may be immediately apparent.

b) The Maternity Hospital Experience

Based on interviews, it seems clear that for many HIV-infected mothers, time spent in the maternity hospital is extraordinarily unpleasant, as a result of the attitudes of the staff. For example, some women recalled that no one washed them after delivery. One young woman recounted with tears in her eyes how she lay unattended in a puddle of her own blood for so long that she literally "dried" to the sheet on the metal bed where she gave birth. Others remembered that the ward floors and toilets were never washed—except by the recovering mothers themselves. Several women emphasized the never-ending stream of criticism and derision directed their way: "Why did you give birth if you've got HIV?" "Well, are you going to take [the child] or leave him here?" In one particularly horrifying case, related by the head of a regional AIDS center, a woman

⁸ The actual rate of perinatal infection among children who are living in families is difficult to establish, because some parents never bring their children in to be tested.

who arrived at a local maternity hospital in labor was left unattended by the frightened staff to deliver the child by herself, during which the baby died.

The HIV-infected women we surveyed reported that many healthcare workers behaved professionally, showing deep sympathy and concern. The women remembered these staff members with warmth. Nevertheless, in one-on-one interviews conducted during the preparation of this report, there was an obvious tendency: negative recollections clearly outweighed the positive ones. The authors of the UNICEF study likewise emphasized "the negative attitude toward HIV-infected persons on the part of medical personnel," which they attributed to low wages, frequent shortages of protective gear (disposable gloves, gowns, linens, instruments), and often the absence of emergency supplies of antiretroviral drugs for use in case of accidental occupational exposure [21].

Experts from the regional AIDS Centers also cite the prejudice exhibited by the staff at healthcare facilities that do not provide specialized services to HIV-infected patients. Such attitudes on the part of healthcare workers may be the result of exaggerated fears about the risks of becoming infected, which are rooted in a lack of knowledge about HIV/AIDS and the ways in which it can be transmitted. Ye. V. Sokolova reports that when replying to the previously cited survey of obstetrician-gynecologists, some respondents mentioned tears, saliva, and urine as possible sources of infection [16]. This study demonstrates clearly the link between a low level of knowledge about HIV/AIDS on the part of healthcare workers and their negative attitude toward HIV-infected pregnant women.

c) Drug Withdrawal

In some instances, women who use psychotropic substances experience the onset of "withdrawal syndrome" during or soon after delivery. Sometimes the woman leaves the maternity hospital in search of drugs, before her child is ready for discharge—in essence, leaving him or her forever. While there are no statistics available indicating the frequency of this phenomenon, some specialists, in the course of interviews conducted during the preparation of this report, advocated the use of narcotic analgesics in obstetric hospitals for the suppression of withdrawal syndrome. Such a measure would give the woman the opportunity (and time) to approach in more balanced fashion the decision about her child's fate; and, in cases where she did decide to relinquish her child, time to complete the necessary documents. A juridically correct declaration of relinquishment would make it possible to avoid the difficulties that often arise in attempting to place children in a family or an infant home when there are no documents officially confirming the relinquishment decision.

d) Fear of the Future

It bears emphasizing again and again that the circumstances of many HIV-infected mothers, especially those who sooner or later abandon their children, are extremely difficult. Many women are poor, young, uneducated, and lacking friends, sympathetic relatives, or other sources of social support. Some are drug users, although often this may be due mainly to a lack of treatment opportunities for drug addiction. It is understandable how difficult it is for women who find themselves in such a situation to provide their child with everything he or she needs. After several months of trying unsuccessfully to cope with the burdens of caring for her infant, some mothers conclude that giving him or her up may be the child's best option.

Such decisions are rarely easy. In the words of one young mother of three children, who a few months earlier left her youngest son at the maternity hospital (the oldest was living with relatives in another region, the middle child was at home):

"I thought about it for a long time. We simply won't be able to cope. He'll need everything, he's ill, of course. He'll need good food. If it were only Stepka [the 18-month-old at home] somehow it would work out, but with two we wouldn't make it. I asked, there at the maternity hospital, what happens if I get everything worked out and I want to get him. They said, write a [relinquishment] declaration now, maybe someone will adopt him, but if you want, come and they'll give him to you, if he's in the little kids' home ... I cried so when I left him there ... Maybe someday everything will work out with me, and I'll be able to get him."

III. Reducing the Risk of Mother-to-Child Transmission of HIV-Infection

Although the availability of antiretroviral (ARV) prophylaxis, designed to reduce the risk of mother-to-child transmission, has improved in recent years, not all HIV-infected mothers receive it, including many of those who are registered for prenatal care. In the 10 regions surveyed for the UNICEF study, only 40 percent of the HIV-infected women who eventually gave birth, on average, received ARV prophylaxis during pregnancy. Roughly 60% of the women and/or their newborn infants, according to this study, received prophylactic treatment during or following delivery (Table 2.3) [8:37].

Table 2.6

Administration of ARV prophylaxis to prevent mother-to-child transmission of HIV-infection, Altay territory and Irkutsk region, 1999-2004 (absolute numbers)

	ARV prophylaxis regimen			
	None	At/after delivery or interrupted during pregnancy	Complete 3-stage treatment	Total
No. women who abandoned child	23	9	3	35
No. women who did not abandon child	13	13	24	50
Total	36	22	27	85

Source: Altay and Irkutsk regional AIDS centers.

Note:

Data in the table are derived from patient records of randomly selected samples of HIV-infected mothers, stratified by those who and did not abandon a child (total N = 85).

Unfortunately, the available evidence does not allow one to state with confidence whether receiving (or not receiving) ARV prophylaxis has any effect on the frequency of child abandonment, that is, independent of other factors. A statistical analysis of data obtained in the course of our research does allow us to present some preliminary findings regarding this question. Data from two regions show a statistically significant association ($p < 0.001$) between child abandonment and whether or not the mother received ARV prophylaxis during pregnancy (Table 2.6). However, the size of the sample on which this analysis is based is unsatisfactory, in our opinion, and allows only preliminary conclusions that require further research. At the same time, it should be pointed out that some HIV-infected women give birth, not knowing that the likelihood that their child will become infected is significantly less than 100% even without ARV prophylaxis, or that the risk of transmission can be lowered even more with it. These mothers expect their children to become HIV-infected. Currently, however, there is no way of knowing whether such a belief plays any role in a mother's decision to relinquish her child.

In recent years, the Russian Government has taken a number of important steps to improve policies intended to prevent the transmission of HIV-infection from mother-to-child and to improve understanding of this issue, specifically:

- In April 1999, the Ministry of Health established the Applied Research Center for the Prevention and Treatment of HIV-Infection in Pregnant Women and Children, as part of the Republic Clinical Infectious Diseases Hospital (RKIB) located outside St. Petersburg (Order No. 133, dated 19 April 1999).
- In June 2003, the Ministry established a Coordinating Council for the Prevention of Mother-to-Child Transmission of HIV-Infection (Order No. 235, dated 09 June 2003). Membership on the council includes representatives from the ministry and various healthcare institutions, other government agencies, and the major international organizations engaged in fighting the HIV/AIDS epidemic. The Council's main responsibility is to coordinate, and to heighten the impact of, various MTCT prevention programs that have been launched in Russia.
- As discussed in Chapter One, steps were taken in September 2003 and January 2004 to improve the epidemiological surveillance and analysis of perinatal HIV-infection.
- In December 2003, the Ministry of Health issued new practice guidelines (Order No. 606, dated 19 December 2003), aimed at strengthening and systematizing the testing and treatment protocols used to prevent MTCT of HIV-infection.
- In 2003, the Ministry of Health, together with the RKIB and UNICEF, sponsored detailed field research into conditions in 10 regions characterized by high prevalence levels of HIV-infection, which generated a substantial amount of new and valuable information.

Meanwhile, at the regional and municipal level, programs aimed at the prevention of mother-to-child transmission of HIV-infection have been underway for several years. In the 10 regions surveyed for the UNICEF Report, standard regimens of ARV prophylaxis (the same used all over the world) are provided to more than half of the HIV-infected women who eventually give birth. In Moscow city in 2003, 74% of HIV-infected pregnant women received ARV prophylaxis during their pregnancies; and all women who did not

receive it during pregnancy were given prophylaxis during delivery. At the same time, a number of civic and international organizations (e.g. AIDS Foundation East-West) have launched "pilot" projects in various regions, designed to strengthen the impact of programs to prevent the spread of HIV-infection, and to educate the larger medical community about HIV/AIDS and various issues related to perinatal infection.

Collectively, these efforts have yielded some impressive results. Recent studies have shown that when only emergency ARV prophylaxis at delivery has been administered and the mother has refrained from breastfeeding, the rate of transmission has been reduced to roughly 12%. When the full multi-stage regimen of ARV prophylaxis was provided (and the mother did not breastfeed), the transmission rate fell to 5% [17].

Still, there is much yet to be done. Partly because multi-stage ARV prophylaxis is administered relatively infrequently, the overall rate of MTCT in the Russian Federation is approximately 15–20%.⁹ In order to reduce the rate of transmission, major improvements are needed in the supply and availability of both anti-retroviral medicines and diagnostic equipment. In this connection, the shortage of rapid-test kits is cause for special concern, for such kits are critical in cases where a woman presenting for delivery is not listed on the pregnancy registry and has not been tested for HIV. As the authors of the UNICEF study emphasize, rapid-test kits should be available at all maternity hospitals, without exception.

Evidence suggests that healthcare workers generally have a low level of knowledge about HIV/AIDS and about the ways HIV-infection can be transmitted. A lack of knowledge, combined with exaggerated fears about the risk of infection and prejudice toward HIV-infected women, constitute major obstacles impeding the successful realization of programs aimed at reducing the transmission of infection.

There needs to be a more intensive effort to identify HIV-infected pregnant women who are not receiving prenatal care. This may be the single most important step that should be taken in order to heighten the impact of policies intended to prevent child abandonment. To be sure, these women are a very difficult group of patients to work with. Most suffer from a wide array of problems besides HIV-infection (poverty, drug dependency, a lack of family and social support), and many strenuously avoid contact with the public healthcare system.

It may take years to overcome the stigmatization of persons living with HIV/AIDS—and to improve the opinions of persons living with HIV/AIDS toward the public healthcare system. Clearly new strategies are called for. Coercive or so-called administrative methods may only worsen the problem, driving even more women to avoid the "attention" of state institutions. Moreover, in view of the suspicion with which many of these women view the state, it is doubtful that healthcare workers can succeed in finding women who are not on the pregnancy registry. Such work requires special skills and the establishment of trust. The effectiveness of such work might be elevated significantly by involving representatives from civic organizations, who, acting in concert with healthcare workers, might be able to work directly with those women who fail to seek prenatal care in surroundings that are familiar to them (this issue is examined in more detail in the concluding chapter).

⁹ Ye.V. Sokolova estimates [17] the rate of transmission nationally to be 19.3% for children born prior to the year, 2000. In light of the significant increase in the availability of ARV prophylaxis since then [21], it is very likely that this number has fallen.

Chapter 3. The Diagnosis, Residential Placement and Social Protection of Children Born to HIV-Infected Women

Unfortunately, there are no national statistics that describe what happens to the children of HIV-infected mothers after they have been discharged from the maternity hospital. The best data on this question are contained in the UNICEF Report. This study found that of 5,115 children born to HIV-infected mothers between the start of the epidemic and mid-2003 (and still living in one of the 10 surveyed regions), about 90 percent lived with one or both of their parents, while 10 percent had been abandoned and left to the care of the state. As shown in Table 3.1, of the 542 abandoned children identified by researchers, more than half (54%) were living in infant homes, nearly a third (30%) were still hospitalized, and only a sixth (17%) had been placed with "substitute families," i.e. adopted, taken in by a guardian (*opekun*), or placed in long-term foster care (*priemnyye, patronatnyye sem'i*).

Table 3.1
Residential placements of abandoned children born to HIV-infected women, 11 regions, 1987 — early 2003 (as of the end of the study period)

Category	Irkutsk region	Kaliningrad region	Leningrad region	Moscow region	Orenburg region	Samara region	Sverdlovsk region	Yekaterinburg	St. Petersburg	Tatarstan republic	Chelyabinsk region	Total	%, total
No. children born to HIV+ women*	672	230	263	533	246	630	595	467	970	150	332	5,088	
of whom:													
% abandoned	11%	18%	10%	7%	6%	10%	2%	9%	18%	10%	11%	11%	
No. abandoned children born to HIV+ women	76	42	27	37	14	61	13	44	176	15	37	542	
of whom:													
% in "substitute families"***	17%	40%	7%	3%	14%	7%	8%	18%	23%	--	5%	90	17%
% in infant homes***	80%	45%	26%	51%	50%	85%	23%	27%	46%	13%	78%	292	54%
% in hospitals****	3%	14%	67%	46%	36%	8%	69%	55%	31%	87%	16%	160	30%

Source: [21]. See Table 1.3 for an explanation of the time periods covered.

Notes:

* Includes children still living in region and for whom there is sufficient information.

** Includes children living with adoptive parents and guardians and in long-term foster care.

*** Includes both traditional and specialized facilities (e.g. "Aystyonok" center in Irkutsk, specialized kindergarten in Kaliningrad).

**** Includes 21 children residing at the Republic Clinical Infectious Diseases Hospital.

There are at least two striking features of these data. One is the large number of children who were still in the hospital, even though in the vast majority of cases, there was no medical justification for it. At least at first glance, this fact is difficult to explain, because virtually all experts agree that prolonged hospitalization is extremely detrimental for infant children's physical, intellectual, and emotional development and, therefore, should be avoided if at all possible. A second striking feature of these data is the very low percentage of family placements, especially compared to placements in institutions. In this respect, too, virtually all experts agree that upbringing in a family is preferable to upbringing in an institution. Indeed, of the roughly 700,000 minor children in Russia who, at the end of 2002, were officially identified as orphans and/or deprived of parental supervision, most were living in families—either adopted (22%) or with guardians (52%)—while just over a fourth (27%) were living in institutions [1:110].

This chapter has two goals. The first is to analyze in detail the questions posed by the data in Table 3.1, namely: Why do so many abandoned children spend such long periods of time in hospitals? And why are so few abandoned children placed with families? Our second goal is to examine other aspects of the lives of children born to HIV-infected women—not only abandoned children, but children still living with their parents as well.

I. Diagnosis of HIV–Infection in Perinatally Exposed Children

By all accounts, the main reasons why abandoned children born to HIV-infected mothers remain hospitalized unnecessarily are: on the one hand, prejudice toward the disease on the part of many government officials, healthcare workers, and members of the general public, particularly a fear that perinatally exposed children might infect others; and, on the other hand, a widespread belief that these children are weaker and generally more difficult to care for. Fear and prejudice have deterred not only would-be guardians and adoptive and foster parents, but also the staff of the institutions responsible for caring for other abandoned children who are uninfected. In fact, the risk of infection as a result of occupational exposure is extremely small, statistically, and the risk of infection by an infant is miniscule [29; 19]. Moreover, while it is true that HIV-infected children do tend to be weaker than uninfected children, at least initially in only a very small percentage of cases does the child require more specialized care than what can normally be provided on an out-patient basis or in ordinary children's homes [5].

In addition, it should be emphasized that most children born to HIV-infected women will **not** become infected themselves as a result of their perinatal exposure (in Russia, this is already the case more than 80% of the time). However, until their HIV status is established officially, all perinatally exposed children are regarded as potentially at risk for acquiring the virus and for infecting others. In view of the negative effects of prolonged hospital stays due to society's prejudice towards HIV, and also keeping in mind the additional costs to the government associated with the creation of specialized institutions for perinatally exposed children, it would seem to be clearly in the interest of each child born to an HIV-infected woman and of society as a whole to ensure that diagnoses of perinatally exposed children are made as quickly as possible. It also is very much in the interest of perinatally **infected** children to receive an early diagnosis, insofar as this can facilitate the prompt start of prophylaxis of opportunistic infections and, if necessary, of antiretroviral treatment.

The diagnosis of a perinatally exposed infant is complicated by the presence in the child's blood of maternal antibodies to HIV that persist for months after the child's birth. In a majority of cases where the child himself is not infected, these antibodies disappear within six months, and in all but a very small percentage of cases, no antibodies to HIV can be detected at 12 months of age [15:329]. Nevertheless, the presence of maternal antibodies makes the most commonly used tests for HIV infection (which are based on detection of the antibodies) unsuitable for diagnosing young infants, although repeated negative results — in the absence of breastfeeding — are regarded in most countries as conclusive evidence of no infection at 12 months of age or even earlier.

Because antibody tests are unreliable for diagnosing HIV infection in perinatally exposed infants, a different approach is recommended, based on detection of the virus itself (as opposed to antibodies to the virus). Although several different technologies are available, the most accurate and widely used is a polymerase chain reaction assay (PCR). A battery of PCR tests can establish conclusively whether or not the child is infected — either positively or negatively — at 6 months after birth [15:330].¹⁰

¹⁰ In the United States, current case definitions issued by the Centers for Disease Control and Prevention (CDC) provide for the following diagnostic standards: for positive diagnoses, at least two positive virologic (non-antibody) tests performed at any time after the child's birth (except for p24 antigen tests, in which case the child should be > one month of age); for negative diagnoses, either two negative antibody tests obtained from child > 6 months of age, or two negative virologic tests (e.g. PCR), at least one of which was obtained from child > four months of age [24]. A recent study, based on medical records of infants born in New York City, 1997–2001, argues that the latter limit can probably be lowered to three months [32].

Virologic tests are used routinely in the United States and most European countries to diagnose or rule out HIV infection in infants. There is some evidence that sensitivity levels of the earliest PCR assays were significantly reduced in the case of non-subtype B strains of HIV-1, including subtype A, the most prevalent strain in Russia. However, the newer PCR assays are characterized by higher levels of sensitivity and specificity, including when used for detecting subtype A strains [7].

Empirically in Russia, a majority of perinatally exposed children are diagnosed officially between the ages of 18 and 24 months, although in some cases the child's HIV status is not established until the child is between the ages of 24 and 36 months, or older.

- Of the 5,115 living children born to HIV-infected women in the 10 regions surveyed for the UNICEF Report, just 15% had received an official diagnosis at the time the research was conducted (Table 3.2).
- In St. Petersburg as of May-2004, of the nearly 600 perinatally exposed children for whom there were data, official diagnoses had been provided for: 84% of children older than 36 months; 77% of children aged 24-36 months, 21% of children aged 12-24 months; and no child younger than 12 months (Table 3.3). In the case of the 16% of children older than 3 who had not been diagnosed, either the parent had not brought the child to the AIDS center for testing, or there was no information on the child's whereabouts.
- In Krasnoyarsk Territory as of mid-2004, 72% of 390 perinatally exposed children had not yet received an official diagnosis, although 38% of these children had been born in 2002 or earlier.

Table 3.2

Diagnoses of HIV-infection in perinatally exposed children, 11 regions, 1987 — early 2003

Category	Irkutsk region	Kaliningrad region	Leningrad region	Moscow region	Orenburg region	Samara region	Sverdlovsk region	Yekaterin-burg	St. Petersburg	Tatarstan republic	Chelyabinsk region	Total
No. children born to HIV+ women	672	230	263	533	246	630	595	467	977	170	332	5,115
of whom:												
confirmed HIV+	19	19	12	14	4	8	6	10	31	11	14	148
confirmed HIV-	38	101	38	67	19	19	25	81	173	18	34	613
transmission rate	33%	16%	24%	17%	17%	30%	19%	11%	15%	38%	29%	19.4%
HIV-status undetermined	615	110	213	452	223	603	564	376	773	141	284	4,354
as % of children of HIV+ women	92%	48%	81%	85%	91%	96%	95%	81%	79%	83%	86%	85.1%

Source: [21]

Table 3.3

Diagnoses of HIV-infection in perinatally exposed children by current age, St. Petersburg (as of May-2004)

	Age of child (years)					
	0-1	1-2	2-3	> 3	Total	%, total
No. children born to HIV-infected women	216	253	88	32	589	
of whom:						
confirmed HIV-infected	0	5	4	4	13	2%
confirmed HIV-uninfected	0	48	64	23	135	23%
HIV-status undetermined	216	200	20	5	441	75%

Source: St. Petersburg AIDS Center

This situation may improve somewhat as a result of changes in the regulatory environment that were introduced in late 2003. Up until then, the only official guidance concerning the diagnosis of HIV-infection in young children was contained in Russian Ministry of Health Order No. 170, dated 16 August 1994, which stipulated that a perinatally exposed child should be listed on the HIV-infection registry [that is, provisionally] until he or she has reached the age of three, at which point an official diagnosis could be established. However, as knowledge and experience increased in the years following this Order, leading Russian AIDS experts published a number of works explaining how HIV-infection could be diagnosed in infants by the age of 18 months, or even earlier using PCR assays [6; 15].

The situation changed officially in December 2003, when the Ministry of Health issued new practice guidelines on the prevention of mother-to-child transmission (MTCT) of HIV-infection (Russian Ministry of Health Order No. 606, 19.12.2003). According to this document (Paragraph 9.8), "a child born to an HIV-infected mother can be removed from the [HIV] dispensary registry at the age of 18 months given the following conditions, all of which must be present: a negative result of an ELISA HIV-antibody test; the absence of hypogammaglobulinemia; and the absence of clinical indications of HIV-infection." PCR assays are not mentioned, however.

It should be noted that PCR assays are a relatively expensive method of testing for HIV and that a substantial initial investment in equipment is required as well [37]. On the other hand, unless there is official authorization permitting the use of virologic tests for this purpose, there can be no early diagnoses of HIV-infection in children, even in regions that already have the necessary laboratory capacity for conducting PCR assays.

Thus, although Order No. 606 may speed up the diagnoses of a few children, its effect overall is likely to be smaller than desired. During our interviews, some healthcare workers indicated that they preferred not to take any chances and so, as a rule, would not remove a child from the HIV registry until after he or she turned three regardless. Many experts believe that the diagnosis of children perinatally exposed to HIV-infection remains an extremely important, urgent, and unresolved issue.

II. The Residential Placement of Abandoned Children

It is difficult nowadays to find any expert-pedagogue, psychologist, pediatrician-who would contend that institutions are a better place for raising orphaned children than families. Compared to children raised in families, the "graduates" of Russian orphanages are more likely: to go to jail, to end up jobless or homeless, to use drugs and abuse alcohol, and even to commit suicide [11]. Specialists in the Russian Ministry of Education, which oversees the network of state-run orphanages for children aged 4 and older, describe the typical product of this system as characterized by: "an undeveloped social intellect, dependency, heightened sensitivity, an exaggerated (or excessively low) sense of self-esteem, a lack of ambition, no understanding of the material dimension of life or respect for property, and a readiness to engage in various asocial behaviors" [4:66]. Given such indictments, the lengthy hospital stays experienced by so many abandoned children born to HIV-infected women and the small numbers that are eventually placed in families call out for an explanation.

a) Hospitals

In most of the 10 regions surveyed for the UNICEF study, researchers found that abandoned infants born to HIV-infected mothers commonly spend their first 4-18 months of life in an infectious disease or isolation hospital [21]. Although a small number of these children (perhaps 10%) develop clinical indications of the early progression of the infection or suffer from opportunistic infections requiring hospitalization, for most of these children a prolonged hospital stay is not medically necessary. They remain in the hospital because there is nowhere else for them to go.

Based on newspaper articles and interviews, it is clear that many hospital staff sympathize with the plight of these children and do what they can to provide them with warmth and attention. However, most hospital staff are overworked. And some are afraid of becoming infected. In the UNICEF study, researchers found that healthcare workers everywhere complained repeatedly about: inadequate monetary compensation for the risks they believe they face; chronic shortages of protective gowns and gloves; and the lack of emergency antiretroviral drugs for use in cases of accidental needle-sticks and other instances of occupational exposure [21]. Because of prejudice on the part of the medical staff, many children with an "unconfirmed diagnosis" are kept in small isolation cubicles, attended by physicians and nurses hidden behind masks, gowns, and gloves. Such children are severely deprived of intellectual, sensory and emotional stimulation and tenderness, which leads, in turn, to physical, intellectual, and emotional stunting that is more serious and less reversible the older they become. Some children spend so much time in relative isolation that they develop what a few observers have labeled the "Mowgli syndrome," in reference to the Kipling story about an orphaned infant left in the jungle to be raised by wild animals [9]. Many children, waiting in hospitals for a conclusive diagnosis of their HIV status, cannot speak, walk, sit on a chair, or eat with a spoon, while their uninfected contemporaries are able to do all of this with ease.

Experts and policymakers alike view this situation as completely unacceptable [e.g. 13]. In a few regions, physicians, local governments, and civic organizations are making special efforts to make children's hospital stays less joyless. In some hospitals, teachers and psychologists have been brought in, game rooms and playgrounds have been created, better food has been provided, and so forth.

Nevertheless, the issue persists: healthy children continue to live in hospitals, because in most regions there is broad opposition to placing undiagnosed children in non-specialized institutions. Many experts believe that clear, assertive guidance from the Ministries of Health and Education could alter this situation. Still, it seems clear that until there is a fundamental lessening of the stigma surrounding children born to HIV-infected women—less ignorance and more compassion—unnecessarily prolonged hospital stays and all the problems that result (the "Mowgli children") will be a continuing problem.

b) Infant Homes

As suggested by the figures in Table 3.1, the overwhelming majority of children abandoned by their HIV-infected mothers eventually end up in infant homes operated by the public healthcare system. However, for **all** HIV-infected children, for **most** undiagnosed children, and even for **some** children diagnosed as uninfected, these are likely to be **specialized** infant homes (or specialized wings of ordinary homes), that is, facilities reserved mainly, and sometimes exclusively, for children perinatally exposed to HIV-infection.

At the local level, where placement decisions actually are made, there exists a strong preference among most AIDS experts and public health officials for keeping all abandoned children born to HIV-infected mothers in specialized residential facilities, until they have been officially diagnosed. Many local experts evidently believe that specialized facilities offer the only practical means of getting these children out of the hospital, given the resistance from ordinary infant homes. Moreover, a few experts believe that even if most HIV-infected children do not need specialized medical care initially, they all need special training. In an interview, the director of one regional AIDS center put it this way: "We must teach these children to live with their diagnosis ... explain to them how to behave in one or another situation ... We must adapt them to life in ordinary society. They need to know, for example, that they need to take their medicines regularly, and so on."

On the other hand, opponents of specialized facilities argue that such institutions are medically unnecessary and, even more important, that the practice of isolating these children merely helps to reinforce and perpetuate the terrible stigma surrounding all persons living with HIV/AIDS. Opponents also point out that, because of the relatively small numbers of HIV-infected children, the only way to make specialized institutions large enough to justify their cost is to place **all** perinatally exposed children in them regardless [5].

On balance, there appears to be little objective need for specialized infant and children's homes for those children who have been perinatally exposed to HIV infection. On the contrary, the proliferation of these institutions almost certainly has been driven mainly by the stigma surrounding the disease and those persons living with it. Less obvious, however, are the implications for policy. Without a doubt, prejudice towards HIV/AIDS needs to be defeated, but the people living with this disease could end up suffering most of the costs of the fight. Some of the support for specialized institutions comes from within the community of persons living with HIV/AIDS, some of whom on some occasions view specialized facilities as the only practical way to shield themselves and their children from the effects of stigma. In an interview, a St. Petersburg father (whose HIV-infected child lives at home with her parents) cautiously supported the creation of specialized kindergartens, observing: "Then I can be sure that no one will threaten [my daughter], that no one will say to her the various unpleasant things they say to me."

c) Family Placements

In the 10 regions surveyed for the UNICEF Report, only 90 (17%) of the 542 abandoned children identified at the time of the research had been placed in "substitute families." However, two regions (Kaliningrad, St. Petersburg) together accounted for more than 60% of these placements; in the other eight regions, the percent of abandoned children placed with substitute families was just over 10 percent (Table 3.1). In addition, although no figures are presented in the UNICEF Report, it appears, based on the description of individual regions, that only a very small number of these placements were adoptions. Most children living in "substitute families" appear to have been placed with guardians (usually with a grandmother or other relative). And according to most experts, only children officially diagnosed as uninfected are adopted.

In Russia as a whole in recent years, approximately 30 percent of all children living in infant homes have been adopted each year [1:112]. And while this number may not seem particularly high, it underscores how relatively poor the adoption prospects are for abandoned children born to HIV-infected mothers. The major obstacles are self-evident: besides stigma, there is the long delay in establishing the child's HIV status, as well as the effects of months in the hospital (stunted physical and intellectual development), both of which lessen the child's appeal in the eyes of would-be adopters. And there is also the skepticism of adoption officials who, we were told in interviews, sometimes voice openly their doubts about the wisdom of taking a perinatally exposed child into a family.

Barring a radical change in diagnostic practices, the prospects would seem to be bleak for any significant increase in adoptions of abandoned children born to HIV-infected women. There is no reason to think that

the likelihood of adoption for **HIV-infected** children will grow much in the near future¹¹. But until it becomes the norm to diagnose all perinatally exposed children at a much younger age, **uninfected** children will remain in an equally disadvantageous situation with a very poor chance of being adopted.

However, judging by our interviews and the published analyses of several leading child welfare experts, the prospects for an expansion of various forms of foster care (*priemnyye and patronatnyye sem'i*), even for HIV-infected children, appear to be more promising. Foster parents are "parenting professionals" employed by state orphanages. In some regions, the idea of a "professional family" is being developed aggressively and introduced as the basis of a new model for the residential placement of orphaned and abandoned children. There have already been efforts to place HIV-infected children in foster families in Kaliningrad and Moscow. But before "professional" foster care can become widely practiced in Russia, at least four challenges will have to be met. First, some members of the general public are likely to bridle at the idea of "paying people to parent," and so the public will have to be educated on this score. Second, the relatively small amount of compensation that foster parents receive from the government must be increased; the level of compensation currently being paid cannot possibly motivate adults to dedicate themselves to raising orphaned and abandoned children. Indeed, raising children whose health has been compromised is even more difficult, requiring considerable self-sacrifice. At the same time, and this is a third challenge, procedures need to be developed for recruiting and selecting foster parents that effectively screen out persons who are motivated solely by mercenary concerns. Fourth, financing flows will need to be redirected in order to support foster families, but in such a way that does not provoke opposition from existing infant and children's homes.¹²

As previously mentioned, most of the abandoned children placed in families have been taken in by guardians. In interviews, both guardians and many expert observers claimed that guardianship often is preferred over adoption, because a guardian receives certain benefits and allowances that are unavailable to adoptive parents. Still, the amount of financial support provided to (or on behalf of) children under the care of a guardian is modest at best; and in some regions, according to care-givers, it does not cover the added costs associated with raising a child. Moreover, complex application and eligibility requirements administered by an opaque bureaucracy often make it difficult and time-consuming for guardians to obtain these benefits.

In addition to more financial support, all members of the family that has taken in an orphaned or abandoned child — including the child — often need advice or help from various specialists who are capable of assisting them in adapting to their new roles. Effective support of this sort is provided by independent organizations like *Roditel'skiy most* (Parental Bridge) in St. Petersburg, which not only helps to teach people to become good adoptive parents and guardians, but also serves as a continuing source of advice and assistance for the parents who have "graduated" and accepted a parentless child into their home [4]. The Government needs to state clearly and forcefully that the primary goal should always be to place orphans and abandoned children **in families** — and then it must effectively turn this goal into reality. One of the things that would facilitate the achievement of this goal would be to support a variety of organizations serving future adoptive parents and guardians, as well as foster families. Another thing that would help is greater accountability on the part of every specialist and government official who is responsible for the welfare of children.

III. Older Children and Their Transfer to Children's Homes

The responsibility for abandoned children born to HIV-infected women has, until now, fallen almost entirely on the public healthcare system. At the end of 2003, probably 90 percent or more of these children nationwide were still younger than three. And nearly all of the children who had not been adopted, taken in by a guardian, or placed in foster care were under the supervision of municipal or regional health departments.

However, in 2004 alone, there were approximately 150-200 abandoned children born to HIV-infected women mothers who turned three, the age at which children under state care normally are transferred to children's homes (*detskiye doma*) administered by the public education system; in addition, probably 30-60 of these children are HIV-infected. Next year (2005), these numbers will double (Tables 1.1 and 1.2). Already, the public education system in many regions is showing a biased attitude toward HIV-infected children, by refusing to accept them in ordinary children's homes.

¹¹ HIV-infected adults who might be willing to adopt an HIV-infected child presently are forbidden by law from doing so [9].

¹² An extremely illuminating, even inspiring description of generally successful efforts to establish professional foster care (*patronatnyye sem'i*) in Perm' region is presented in a recent book, *Ways to Resolve the Orphan Problem in Russia* [11:175-92].

- Recently, in a large industrial city in the Urals, the issue arose regarding the need to transfer a four-year old child who is HIV-positive from a specialized infant home to a children's home. The local AIDS Center strenuously opposed this, declaring that the transfer of an HIV-infected child to an ordinary children's home is impossible, even if the child in question is completely healthy in all respects except for his HIV status. Both the AIDS Center staff and local education officials evidently hoped that the RKIB would take the child. However, their request was refused, and the child is continuing to live in the infant home. In an interview, the infant home director lamented the fact that "the local education system is not prepared to accept [HIV-infected] children and is not prepared to decide the issue on its own."
- The UNICEF Report found that in the 10 regions covered by the study, "at the time the research was conducted not a single HIV-infected child older than three had been transferred from an infant home to a children's home" [8:60].
- So far, the Ministry of Education has not provided (at least not publicly) any guidance to regional education departments regarding the placement of HIV-infected children; and, when asked, local public health officials are unanimous in their view that the education system simply is unprepared to deal with the coming influx of such children.¹³ At the local level, one often hears suggestions to the effect that HIV-infected children should be transferred to specialized facilities for the developmentally disabled.

The only encouraging sign in this situation is the fact that in late January 2004, the Russian Ministry of Health added a representative from the Russian Ministry of Education to its Coordinating Council on MTCT prevention, specifically for the purpose of strengthening inter-agency coordination (see Ministry of Health Orders No. 25, dated 28 January 2004, and No. 178, dated 01 November 2004). Doubtless one of the most urgent issues requiring significantly improved interagency coordination is the placement and care of abandoned HIV-infected children as they grow older. The experience of a few regions shows that careful coordination between public health and education authorities at the local level can make it possible to deal effectively with the residential placement of abandoned children who have been perinatally exposed to HIV-infection.

IV. Social Protection

A child's risk of abandonment does not end when the mother and her newborn infant leave the maternity hospital. This is true for a number of reasons. The mother's health can worsen, and she may not be able to continue to care for her child. Sometimes a mother will abandon an infant several months after his or her birth, when she realizes that the burden of raising her child is too great. In a few families, even though the child is living with his or her mother, actual responsibility for the child's care and upbringing rests with a grandparent or other relative who, perhaps far from young themselves, may be facing their own health problems, inadequate financial resources, or other difficulties. In this instance, an unexpected change in the care-giver's financial situation, health status, or other circumstances can create an immediate risk of child abandonment. In addition, the placement of an abandoned child in a "substitute" family is not always permanent. Guardianship can be revoked for various reasons, including those listed above. And sometimes a foster family returns a child who turns out to be "too difficult." In other words, a child is always at risk of being abandoned. But that risk is significantly greater for the children of HIV-infected women, because it is more likely that the health of their parents or other care-givers will worsen.

At the same time, abandonment is only one of numerous risks facing all children who have been perinatally exposed to HIV-infection. There is the risk of becoming HIV-infected themselves—this will be true of as many as 25-30% of abandoned children, fewer in the case of those whose mothers received ARV prophylaxis. And if a child does turn out to be HIV-infected, there is the risk of not securing timely access to the antiretroviral drugs necessary to preserve his or her health. For many perinatally exposed children who were not abandoned, there are other risks associated with such things as poverty and their mothers' youth and lack of education and parenting skills; and with the absence of other adults or social support to whom the mother might turn for help in an emergency or when circumstances become especially difficult. For some children, there are the risks resulting from their parents' asocial behavior (drugs, crime, violence).

Full discussion of the specific problems and risks faced by the children of HIV-infected mothers and their families is well beyond the scope of this report, although it is important to acknowledge them. There are, however, three issues that deserve at least brief mention here: (a) the availability of programs aimed at preserving and strengthening families; (b) the access of HIV-infected children to antiretroviral therapy; and (c) social problems resulting from restrictions imposed on the immunization of HIV-infected children.

¹³ Not only the children's homes are unprepared to take HIV-infected children. The public schools are equally unprepared, although it should be noted that an upsurge in the number of HIV-infected children seeking access to the school system is still 2–3 years away.

a) Assisting Families Affected by the HIV Epidemic

Regarding the issue of social support to families, there are a number of programs operating in this field that merit attention. For example, in St. Petersburg a not-for-profit organization, Innovation Center (*Tsentr Innovatsii*), has created a provider of social support to families affected by the epidemic (one hopes there are similar organizations elsewhere).¹⁴ Financed by international donors, Innovation Center offers a wide array of services to poor families, including 20 families selected from a list supplied by the city AIDS Center. Depending on the specific needs of the family, the Center provides in-kind assistance (food baskets suggested by physicians and sometimes medicines), legal advice, mental health counseling, employment assistance, help in filling out documents, and access to specialists in child development. But material assistance isn't all that Innovation Center provides. As one staff member put it in an interview, "our mothers also need a warm soul and heart. Things are so bad for them, they don't need their children, their life is over, they [feel] useless." The Center tries to teach its clients to believe in themselves and their strength and to take responsibility for their own fate.

There are no objective measures demonstrating the effectiveness of Innovation Center. And 20 families is a very small fraction of the thousand-plus families in St. Petersburg with a child born to an HIV-infected mother. Nevertheless, the Center's experience can still help to demonstrate several important points.

First, many HIV-infected women who do not abandon their children continue to live in extremely difficult conditions, in which even the un-infected child is continually exposed to varied dangers threatening his or her future.

Second, the challenges confronting these families and the circumstances of the parents are extraordinarily varied. Some mothers are seriously ill. Some cannot find work or need to work at several low-paying jobs in order to support themselves. Some are trying to finish school or to obtain training so as to secure a better life for themselves and their families. Some abuse alcohol. Some use drugs or, on the contrary, are trying to escape drug dependency. Some are the victims of domestic violence. And in all of this, many are young, single women who have no one they can turn to for help. There is no single solution that could improve the lot of all of these families. Rather, effective assistance to such clients requires not only many different skills, but also an ability to act in accordance with the particular needs of each family. Such actions require large amounts of time and attention devoted to families directly, in their homes, face-to-face.

A third point to be emphasized is that the state does not need to be directly and wholly responsible for solving all social problems. The assistance provided by Innovation Center is difficult, painstaking work, but it is not particularly expensive, nor does it require much capital or highly-trained staff. It does require dedicated, caring people. But all that's needed from the state is a willingness to provide at least some of the resources needed to do the work and to allow the organization to decide how best to use the funds.

b) Access to Antiretroviral Drugs

By the end of 2003, more than 13,000 children had been born to HIV-infected mothers; and in all likelihood between 10-20% of them — i.e. 1,300–2,600 — were (are) HIV-infected themselves. Probably most of these children so far show no clinical indications of the progression of the disease. However, some — perhaps as many as 500 — already need antiretroviral drug therapy in order to keep the disease at bay. While there are no statistics available that would demonstrate this, the available evidence suggests strongly that only a fraction of the children who need antiretroviral drugs are presently receiving them. The authors of the UNICEF study found only "scattered individuals (*yedinichniye deti*)" receiving antiretroviral treatment, which they attributed to a widespread lack of funds to purchase the drugs, but also to a lack of local laboratory capacity for monitoring a patient's immune status and viral load and for testing for drug resistance [8:50]. Sometimes, as happened recently in Perm', according to an interview, local funding runs out, forcing suspension of a child's treatment, which "raises the risk of elevated drug resistance."

To be sure, not all regions are in such desperate straits. For example, as a result of efforts by the Moscow city government and the local AIDS Center, it has been possible to provide needed medicines to all abandoned children in the city who need ARV therapy. At the Republican Clinical Infectious Diseases Hospital outside St. Petersburg, children from all over the country who require specialist care, including 21 abandoned children, are receiving timely treatment. However, many Russian children who need antiretroviral therapy are not so fortunate. Needless to say, this number will inevitably grow, probably at an accelerating pace.

c) The Immunization of HIV-Infected Children and Access to Educational Services

In interviews conducted during the preparation of this report, issues associated with the immunization of perinatally exposed children were raised frequently by parents. These issues go far beyond the bounds of medicine. One problem is the way in which current immunization policies have become an indirect barrier to parents seeking to place their children in kindergartens.

Current practice guidelines state that in most cases, HIV-infected children can follow the same standard

¹⁴ In Irkutsk, there is an analogous organization called "Steps (*Stupeni*)", also financed by international donors, which provides a comparatively narrower range of services to a larger number of children and families (180), and which likewise works in close collaboration with the regional AIDS center.

immunization procedures and schedules as other children. The chief qualifications are (1) that HIV-infected children should not receive BCG, the anti-tuberculosis vaccine, because it contains live bacteria, and (2) that they should receive only dead-virus poliomyelitis vaccine. In addition, it is recommended that immunization schedules be modified in individual cases in accordance with variations in the child's immune status, so that vaccines are administered when immune response is likely to be the greatest; and that HIV-infected children be given additional vaccinations not normally administered to young children [e.g. protection against Hepatitis B and influenza]. Because the HIV status of perinatally exposed children is not established until they are a year and a half old, these guidelines are applied to virtually all HIV-exposed children between the ages 0–18 months.

In some cases, according to parents and other observers, a child's failure to receive BCG vaccine has been used by kindergarten officials as cause for denying the child entry. In other cases, parents believe that the absence of a vaccination or the use of dead-organism vaccines constitute a "red flag" to kindergarten staff who conclude that the child is HIV-infected and then find all sorts of pretexts to reject him or her.

There is a likelihood that, as the number of HIV-infected children grows, and especially as the number seeking entry into the school system rises, this issue will mushroom into a serious controversy. Clearly, the rights and interests of children exposed to HIV need to be better protected than they have been. On the other hand, it is equally clear that all children entering kindergarten or school need to be properly vaccinated against communicable diseases.

There are a number of steps that healthcare officials can take to avert conflict or at least to lessen its severity. First, speeding up the diagnoses of HIV-exposed children should reduce substantially the number of children affected by existing immunization restrictions. Second, current restrictions limiting the use of certain vaccines should be reviewed, taking into account not only the risks associated with a particular vaccine, but also the benefits.¹⁵

¹⁵ Some international experts believe that in regions characterized by a high prevalence of tuberculosis, the benefits of the routine administration of BCG vaccine to all children, including those who are HIV-infected, substantially outweigh the risks [30:546]. On the eve of this report's publication, the Coordinating Council on the Prevention of MTCT of the Ministry of Health issued a recommendation that children who have been perinatally exposed to HIV-infection should be vaccinated against tuberculosis.

Chapter 4. Child Abandonment and its Prevention: International Experience

While working on this report, the authors endeavored to analyze international experience in dealing with the problems of perinatal HIV-infection and child abandonment, which are today so urgent in Russian society. Our research allows us to state confidently that the various issues described in this report are hardly unique to Russia. On the contrary, these are problems that many of the world's countries are facing and trying to deal with effectively. The international community is confronted with difficult challenges that require patience, creativity, and tireless dedication. This chapter presents a brief review of measures adopted by the government in the United States, one of the first countries to face the HIV/AIDS epidemic. This was a deliberate choice on our part, made after a detailed analysis of the situation in several countries. Our choice was dictated in part by America's 20 years' experience in fighting the epidemic, which makes it possible to assess the impact of the government's policies and to draw some conclusions as to which measures have had a positive effect and which have not yielded the expected result.

There are, of course, fundamental differences between Russia and the United States, including the relative size of their economies. American policymakers and healthcare workers have at their disposal considerably more resources with which to deal with the problems associated with the HIV/AIDS epidemic. Nevertheless, there are also some remarkable similarities in terms of the ways in which the two countries' epidemics have evolved. One is the simultaneous outbreak of two epidemics-illegal drugs and HIV-infection-which in both countries led to an upsurge in child abandonment, with many infants unnecessarily hospitalized because local child welfare officials have not known what to do with them. Another similarity is that in both countries sizable numbers of HIV-infected mothers are not identified in time for them to receive ARV prophylaxis aimed at preventing transmission of the infection to their children. As a result, even today there are an unnecessarily large number of children in the U.S. who become perinatally infected with HIV, some of whom fail to learn of their infection until months or sometimes years later.

I. Child Abandonment and the Abandoned Infants Assistance (AIA) Act

The situation taking shape in the United States in the mid-1980s can be characterized by the following excerpt from the work of an American author: "The co-occurring [drug] and HIV epidemics ... gave rise to a dramatic increase in the number of infants exposed to drugs and/or HIV *in utero* and also led to staggering numbers of 'boarder babies' and 'abandoned infants' residing in hospital wards throughout the country" [33:3]. These words are as suitable as any for describing the situation that exists today in Russia. In 1988, in response to the growing problem of abandoned children, many of them born to HIV-infected mothers, the U.S. Congress passed the Abandoned Infants Assistance (AIA) Act, which authorized the U.S. Department of Health and Human Services (DHHS) to fund a series of "pilot" projects around the country, aimed at developing practical interventions and programs for accelerating the discharge of these children from hospitals and their placement with families, ideally in permanent living situations.

Over the next 15 years, the AIA Act was reauthorized several times and broadened somewhat in its scope to include a greater emphasis on prevention and a focus on all children exposed to, or threatened by, parental substance abuse. To date, more than 65 projects have been funded.

The AIA Act was adopted in response to urgent pleas for help received from state and municipal governments and from child welfare advocates, but not because there was strong empirical evidence that described a huge problem. There is no standard reporting in the U.S. of the number of abandoned children; the only recent national-level estimates come from telephone-based surveys of pre-selected hospitals, which were commissioned by DHHS and conducted twice, in 1991 and 1998 [36]. According to the first of these surveys, there were an estimated 9,700 "boarder babies" in U.S. hospitals in 1991 (infants under a year old who remained in the hospital when there was no longer any medical justification for their continued stay because there was no one to take custody of them), as well as an estimated 11,900 "abandoned children" (infants under a year old who remained in the hospital for medical reasons, but who were not expected to leave with a biological parent). Although there may have been some overlap between the categories (some "boarder babies" may previously have been "abandoned infants"), the survey suggested that there were perhaps as many as 20,000 abandoned infants in U.S. hospitals that year, for whom hospital authorities and local child welfare officials needed to find placements (Table 4.1).

The purpose of the AIA Act was to help localities develop means of finding and expediting permanent placements for these children. In recent years, Federal authorities in the U.S. have pressured localities to expedite the

process of finding permanent placements for abandoned and orphaned children. A 1997 Federal law requires states to find permanent placements within 12 months, and some states have set even more stringent limits. It should be emphasized that residential institutions generally are **not** viewed as suitable placements, that is, **the children must be placed with families**. In many states, even long-term foster care is not considered to be a permanent placement [34].

As mentioned previously, the AIA Act has been reauthorized several times and continues in force today. As of April 2002, there were 35 projects still being funded, spread among various regions of the country. Most of these projects can be described as comprehensive, multidisciplinary programs, based either at particular hospitals or in geographically-defined communities, which offer to their enrolled client children and families a broad array of services, such as substance abuse treatment, employment assistance, training in parenting skills, mental health counseling, child development assessments and services, etc. Several projects focus on "permanency planning" for HIV-infected mothers, designed to help ensure that the children receive continued supervision and care, in case the mother become too ill to perform that role or dies [33:47-55].

The immediate clients of AIA programs are infants and children identified as at risk of abandonment, neglect, or abuse by their parents. In practice, in order to protect these children and improve their situation, AIA projects deliver most of their services to the parents, mothers in particular. The mothers enrolled in AIA projects have tended to be extremely disadvantaged by most socio-economic indicators. The majority are single, poorly educated, and jobless. Many have a history of domestic violence and criminal behavior, and many have had children previously removed from their care by the state. Some have worked as prostitutes and/or have sold illegal drugs. And many used drugs or alcohol during pregnancy; indeed, only a third or fewer have never previously been treated for substance abuse (Table 4.2). In the mid-1990s, about a third of enrolled mothers were HIV-infected, although by 2001–2002, the percentage had fallen to less than 20% [28:24].

Table 4.1
Numbers of "boarder babies" and abandoned children in the United States, 1991 and 1998 (based on telephone surveys of pre-selected hospitals)

	1991	1998
"Boarder babies"*		
estimated total for year	9,700	13,400
number born premature, %	47%	35%
low birth weight, %	57%	33%
exposed to drugs <i>in utero</i> , %	79%	65%
average length of hospital stay, days	22	9
– median length of stay, days	5	4
Abandoned children**		
estimated total for year	11,900	17,400
number born premature, %	70%	70%
low birth weight, %	76%	71%
exposed to drugs <i>in utero</i> , %	78%	72%
average length of hospital stay, days	34	34
– median length of stay, days	13	18

Source: [36: 9, 18, 20, 27, 36, 37, 43]

Notes:

Percentages of premature, low birth-weight, and drug-exposed infants, as well as the numbers on average and median lengths of hospital stay, are not estimates for the year but refer only to those infants residing in the hospitals on the day of the survey.

* Defined as children less than a year old "who remain in the hospital beyond the date of medical discharge."

** Defined as children less than a year old "who have not yet been medically discharged but who are unlikely to leave the hospital in the custody of their biological parents."

Despite the enormous challenges presented by such a client group, many evaluations of AIA projects report significant successes. The authors of one summary write: "All of the original projects have discovered that many HIV and/or drug affected families are able to benefit from an array of in-home and community-based services; even families with severe psychosocial problems have been able to respond effectively to interventions that are sensitive to their needs. These families have the capacity to change their behaviors and act in the best interests of their children when provided with supportive, accepting, client-driven, family-focused services" [33:iii] A recent cross-site evaluation, based on data from 28 projects over six years, found that the percentage of mothers reporting employment income nearly doubled between program enrollment and completion (from 12% to 21%), while the number using illegal drugs or alcohol fell by a third (from 45% to 30%). Children of women who received pre-natal services were born healthier, were hospitalized for shorter periods, and were more likely than others to be living with a biological parent at time of program completion [28:28-31].

Table 4.2
Characteristics of mothers served by AIA-funded programs in the United States, 1996-2002

Indicator	Percent of all mothers
Marital status (N=4,837):	
single, never married	71
divorced/separated/widowed	13
Education (N=4,401):	
less than complete high school	56
Sources of cash income (N=3,315):	
paid employment	12
Child-bearing status at time of enrollment (N=5,060):	
pregnant	13
delivered within last 30 days	43
Maternal risk factors :	
history of criminal behavior (N=3,315)	43
child previously removed from home due to abuse/neglect (N=3,552)	39
domestic violence (N=2,901)	41
prostitution (N=1,587)	17
sold drugs (N=1,608)	17
Substance use during pregnancy:	
alcohol (N=3,485)	46
crack cocaine (N=3,655)	51
tobacco (N=3,211)	49
none (N=3,104)	16
History of drug treatment (N=3,065):	
within last 6 months	47
never	29

Source: [28].

Notes: Figures are averages across 6 program years, covering the period, October 1, 1996 through September 30, 2002. Information was provided by 28 projects that reported data. The total number of persons covered by a particular percentage is provided in parentheses; these totals are generally between 30%-50% of all biological mothers enrolled during this 6-year period.

Long-time directors of these projects have distilled a number of important "lessons" from their experience, which may be applicable to similar projects in other settings [33:75-78]. One lesson is the way in which projects over time have come to focus on families as a unit, rather than on just children and parents. Although the projects' primary goal is to keep children in families, project leaders realized that in order to accomplish this, they had to meet the needs and problems of parents and other family members, in order to secure their support for creating and sustaining a cohesive family unit. Second, close collaboration with all interested government agencies and the larger community was essential, partly because so many different services were required and in order to maximize available resources, but also to ensure that agencies acting independently in pursuit of their own goals did not undermine the efforts of the group as a whole. Especially difficult to achieve, but crucial, has been the cooperation of the police and courts. The principal concern of these organizations is to protect the safety of the child and to uphold the law. Yet, it is easy to imagine how the overly aggressive, rigid pursuit of such goals can come into conflict with efforts to preserve intact families suffering from drug and alcohol abuse. On the other hand, the threat of legal or police action has sometimes been a useful prod to keep a balky parent participating in treatment for substance abuse. Third, and perhaps most important has been earning the trust of the parents and their shared commitment to achieving project goals. In practice, this has meant "helping clients as opposed to judging them, listening to them and respecting their goals, developing assessments that make sense to them, and adopting an approach that is flexible and adaptable..." [33:76]. In general, the parents are a difficult group to reach: suspicious, skeptical, often suffering from low self-esteem, prone to depression and passivity, yet easily offended. However, without their active support, no program success is possible.

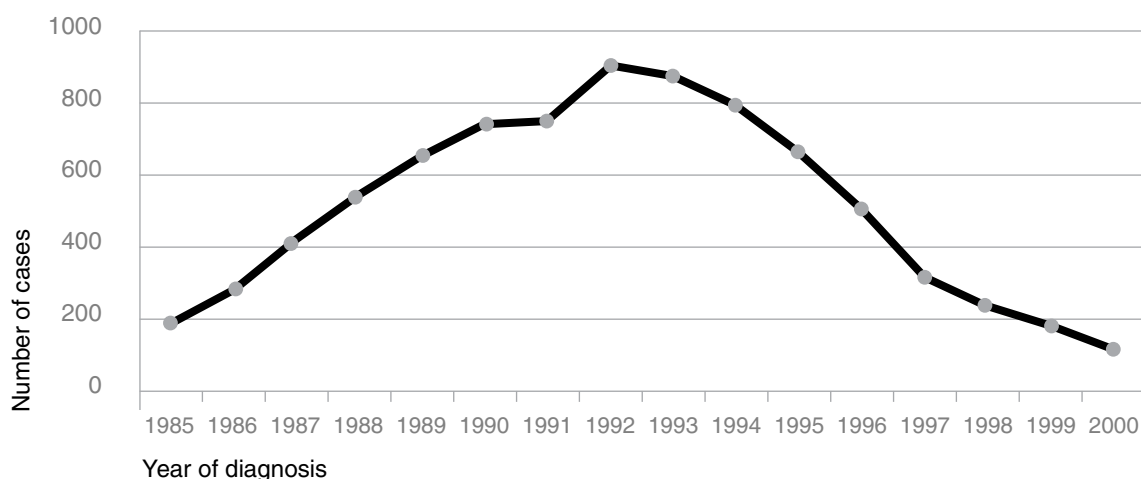
It is difficult to measure the impact of AIA projects at the national level. The DHHS surveys indicate that the number of boarder babies and abandoned infants **increased** between 1991 and 1998, perhaps by as much as 50%. On the other hand, the average length of stay in the hospital beyond medical discharge fell from 22 to 9 days, nearly 60%. In addition, boarder babies in 1998 were somewhat healthier, suggesting that their mothers had received more and/or better prenatal care, although this was not true for children likely to become "abandoned" but not yet ready for medical discharge (Table 4.1). Meanwhile, closer inspection of the DHHS data revealed that in 1991, "boarder babies" were highly concentrated geographically; three large cities (New York, Chicago, Los Angeles) accounted for nearly half (47%) of the total. In contrast, in 1998 although the estimated total number of boarder babies had fallen sharply in two of these cities and in a number of others as well, overall the number of boarder babies had increased by more than 3,500, and now they were found in many more cities throughout the country. While urging caution in interpreting these results, DHHS researchers suggested the following conclusions: "social problems have not declined; rather, the system for rapidly identifying alternative care settings for these infants has improved. In other words, the number of infants requiring child welfare services has increased, as evidenced by the increase in the abandoned infant population. In some urban centers, the resources to meet these needs have improved, thus reducing the number of boarder babies without addressing the more fundamental social issues that create the abandoned infant problem" [36: 46].

These observations suggest, in turn, two broader conclusions. First, one cannot expect AIA-type projects to have much impact on the fundamental social and economic forces that are responsible for creating the problems that these projects are intended to address. For example, the DHHS researchers speculate that the observed change in the geographic dispersion of boarder babies may have been related to changes in illegal drug consumption, namely: the declining popularity of crack cocaine which had fewer sources and was distributed through major transportation routes; and the growing popularity of methamphetamines which could be manufactured locally ("in people's basements, garages") and thus made easily available "in even the most rural areas" [36: 46]. AIA-type projects can help to ameliorate the effects of child abandonment and may even help to prevent it, but they cannot alter the factors that give rise to abandonment in the first place. Second, the relative effectiveness of a project can be manifested in multiple, sometimes contradictory indicators. In principle, creating an infrastructure that enables child abandonment to be treated more effectively may also stimulate abandonment, by making it relatively easier: a) for ambivalent mothers to relinquish their children; and b) for state officials responsible for child welfare to identify children at risk of neglect, abuse, or abandonment and, in some of those cases, to remove those children and place them in a safer, more nurturing environment. In summary, the lack of change in the rate of abandonment (or even an increase) following the establishment of AIA-type programs could be a sign of their success, not failure.

II. Preventing Mother-to-Child Transmission of HIV Infection

By the end of 2001, more than 8,200 cases of perinatally-acquired AIDS (not HIV infection) had been reported in the United States.¹⁶ However, the incidence of new cases, after peaking in 1992, has been falling rapidly. In 2001, just 150 new cases were reported to the Centers for Disease Control and Prevention (CDC), a sixth of the number reported in the early 1990s (Figure 4.1).¹⁷ While the incidence of perinatally-acquired AIDS is not equivalent to the incidence of perinatal HIV-infection, it does track closely over time with the incidence of infection, albeit with a lag. CDC estimates that currently there are approximately 280-370 new cases of perinatal HIV infection annually [25:64]; given an estimated 7,000–8,000 births annually by HIV-infected women, this suggests that transmission of the disease from mother to child occurs roughly 4–5% of the time, on average.

Figure 4.1
Estimated Number of Perinatally Acquired AIDS Cases, by Year of Diagnosis, 1985–2003, United States



Source: CDC

Note: Data adjusted for reporting delays and for estimated proportional redistribution of cases in persons initially reported without an identified risk factor

The principal causes of the dramatic decline in the incidence of perinatally-acquired AIDS (and, by inference, in the incidence of perinatal infection) have been the rapid expansion of prenatal counseling and testing for HIV, in response to the urging of the U.S. Public Health Service in the early 1990s, and especially the dramatically improved access to ARV prophylaxis. In 39 states and territories, the percentage of HIV-infected pregnant women receiving at least part of the standard ARV prophylaxis regimen rose from less than 20% in 1993 to more than 85% in 2000 (Figure 4.2).

Despite these gains, the overall rate of mother-to-child transmission of HIV in the United States remains significantly higher than it could — or should — be.¹⁸ There are still many HIV-infected women who are not identified as infected before giving birth, which prevents them from receiving ARV prophylaxis. Many of these women are unable or unwilling to obtain prenatal care, for reasons often related to poverty and/or drug and alcohol abuse. However, it also is the case that a significant number of infected women who do receive prenatal care are never tested for HIV, either because they decline to be tested or because they are

¹⁶ In the U.S., all 50 states, the District of Columbia, and all territories report cases of perinatally-acquired AIDS to CDC, using the same case definitions and reporting forms. Not all states do so with respect to HIV-infection, and surveillance of HIV-infection differs across states, which makes the aggregate reporting of HIV infection less reliable than reporting of AIDS. For a description of the limitations in U.S. surveillance practices, see the "technical notes" at the end of the annual CDC HIV/AIDS surveillance reports, available at the CDC website: <http://www.cdc.gov/hiv/surveillance.htm>

¹⁷ These data, as well as Figures 4.1 and 4.2, are taken from the CDC website, at: <http://www.cdc.gov/hiv/graphics/pediatric.htm>

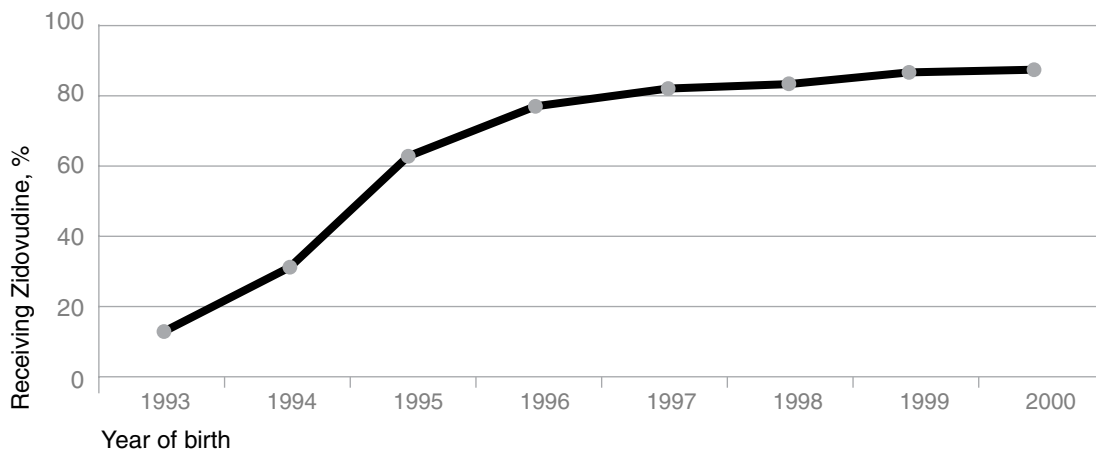
¹⁸ Studies from 1996-2000 found transmission rates of less than 1% for women with no detectable viral load; and less than 2% for women receiving either combination antiretroviral therapy or zidovudine-plus-cesarean section delivery [25:66].

never offered testing. The CDC reports that, on average, a little more than two-thirds of pregnant women who are offered testing accept it [25:68], while various studies suggest that, overall, perhaps as many as half of HIV-infected pregnant women are not tested prior to giving birth. Studies from the early 1990s indicate that in approximately a third of cases of perinatal infection, the mothers had not been tested for HIV before they gave birth [27].

As a result of such data, much of the attention of those officials and activists most concerned with reducing perinatal infection in the U.S. has been focused on how to increase the rate of HIV testing among pregnant women. Many experts have advocated the introduction of prompt compulsory screening of new-born infants, which would permit short-course neonatal prophylaxis for positively diagnosed infants that could prevent at least some cases of perinatal infection. However, some physicians and many activists have opposed this, on grounds that it would compromise the mother's right to privacy, and as of 2001, compulsory screening of new-born infants had been established in only two states, New York and Connecticut [27].

Figure 4.2

Zidovudine Use for HIV-infected Pregnant Women or for Perinatally Exposed* or Infected Children Born 1993–2003, 41 Areas



Источник: CDC

Note: Includes prenatal, intrapartum, or neonatal receipt of Zidovudine to reduce perinatal HIV transmission. As of 2003, 41 areas conduct name-based HIV surveillance.

* Perinatal exposure data from 29 areas that report perinatal exposure.

Because of the opposition to compulsory screening, attention currently is focused on the effort to make HIV testing a routine component of prenatal testing that is offered to all pregnant women seeking prenatal care, which women can then reject if they wish. In this model, labeled the "opt-out" approach to testing, an HIV test is ordered as part of the battery of tests normally administered to a pregnant woman when she first seeks care, without specifically drawing her attention to the problem of HIV-infection and thereby forcing the woman to consider whether or not she might be infected. The healthcare provider in this case takes no part in the woman's decision-making process. Traditionally in the U.S., the so-called "opt-in" approach has been utilized, which presupposes first counseling the woman about the various ways HIV-infection can be acquired and the risk of passing the virus to one's newborn child, and then offering an HIV test. According to data reported to the CDC, in 8 states using the "opt-in" approach, between a fourth and two-thirds of pregnant women are tested, while in one state using an "opt-out" approach, a testing rate of 85% has been achieved [26].

Chapter 5. Conclusions and Recommendations

The goal of this chapter is to emphasize once more the main conclusions of previous chapters and to suggest steps which the Russian Government could take: (1) to reduce the amount of child abandonment; and (2) to reduce the personal, social and economic effects of abandonment-chieflly by speeding up the discharge from hospitals of perinatally exposed children, by facilitating the placement of more abandoned children in families, and by lessening the isolation of these children from the rest of society.

Change the Attitudes of Healthcare Workers Toward Persons Living with HIV/AIDS

One of the greatest obstacles impeding efforts to slow the spreading HIV/AIDS epidemic in Russia is the stigma surrounding this disease and the people afflicted by it. One of the findings of this study that merits particular attention is that healthcare workers-who should be more knowledgeable about HIV/AIDS than other people and who ought to show greater compassion toward persons living with this disease-in fact often help to reinforce and perpetuate the stigma and display indifference toward their patients. Of course, this is not true of all healthcare workers. On the contrary, there are many physicians, nurses, and other medical personnel throughout the Russian Federation who are extremely knowledgeable about HIV/AIDS and who are compassionate and caring toward their patients. Nevertheless, it needs to be emphasized again that there can be no hope of changing society's prejudice toward persons living with HIV/AIDS without widespread support and assistance from healthcare professionals. Both for the Federal Ministry of Health and for regional and municipal public health departments, Priority Number One in the fight against HIV/AIDS must be to improve all healthcare workers' knowledge about the disease and to encourage their compassion towards persons living with it.

The stigma associated with HIV/AIDS is one of the factors that worsen child abandonment, insofar as it discourages some women from seeking medical care. The result is more unwanted pregnancies and more HIV-infected infants. Stigma also degrades the children's quality of life. Stigma is the reason why abandoned children spend needless months in hospitals, which can permanently retard their development and all but end their chance at adoption. Yet, even after their discharge from the hospital, these children face continuing isolation from the rest of society. And the prejudice directed at those persons living with HIV who keep their children compounds their family's plight and their children's continuing exposure to the risk of abandonment.

All healthcare workers in all healthcare facilities need to be better informed about HIV/AIDS. At the same time, workers' fears need to be taken seriously. A critical step in strengthening healthcare workers' safety would be to clarify all of the risks that health workers face, when treating and caring for patients who may be HIV-infected. It is vital that more scientific investigations be conducted of the empirical risks of infection as a result of occupational exposure to HIV, based on clinical experience both in Russia and elsewhere. Relevant studies from other countries that have been published in international journals [e.g. 29] should be translated into Russian and disseminated widely.

A formal program to elevate healthcare workers' level of information about HIV/AIDS should be developed and implemented in the nearest future. Despite the fact that considerable time will be needed to institute such a program, given the huge scale of the public healthcare system, the planning and implementation of this program must become a priority of public health authorities at all levels.

Better information about HIV/AIDS and an increased understanding of the risks of infection will not, by themselves, improve healthcare workers' safety. And in order for healthcare workers to fulfill their professional obligations properly, they must feel safer. The UNICEF Report demonstrated that there exists widespread dissatisfaction among healthcare workers, due to shortages of essential drugs, protective clothing, and supplies. At a minimum, all healthcare facilities should have prompt access to antiretroviral drugs for use in case of accidental exposure to HIV. There should be specially selected staff in all healthcare facilities, trained in the use of prophylaxis protocols in cases of accidental exposure. And healthcare workers must be better supplied with latex gloves and disposable instruments.

The Need for Early Diagnoses of Perinatally Exposed Children

Delayed diagnoses of HIV-infection are the main cause of the prolonged hospitalizations of perinatally exposed infants and almost certainly are the main reason why abandoned children born to HIV-infected women are adopted so infrequently. Perinatally exposed children need to be diagnosed as early as possible. And in view of the enormous social expenditures associated with the unnecessarily long hospital stays, the low adoption rates, and the proliferation of medically unnecessary specialized residential facilities, it is clear that society likewise shares an interest in the earliest possible determination of the HIV-status of these children.

When it comes to dealing with perinatal exposure to HIV-infection and child abandonment, **there is no greater or more urgent priority that to ensure the earliest possible diagnosis for all children born to HIV-infected women.** In this connection, no single step that the Russian Ministry of Health and Social Development could take would have a more immediate or far-reaching impact on the lives of these children than the issuance of new diagnostic guidelines for children who have been perinatally exposed to HIV-infection. New guidelines should differentiate between positive (infected) and negative (un-infected) diagnoses; and they should affirm the juridical validity of virologic testing methods. The cost of this technology is continuing to fall, thereby helping to increase its accessibility. The goal should be to ensure that virologic testing is available to all children who need it in the nearest future.

Increase Participation in Prenatal Care

Sizable numbers of HIV-infected women, in Russian and many other countries, fail to seek medical care in the early stages of pregnancy; and the evidence indicates that these women account for a disproportionate share of unwanted pregnancies, cases of perinatal HIV infection, and abandoned children. In order to reduce the rate of mother-to-child transmission of HIV and the amount of child abandonment, it is essential to find a way to extend early prenatal care to more of these women. Unfortunately, experience in Russia and elsewhere suggests that this is no easy task. Many HIV-infected women who do not receive prenatal care are poor, young, poorly educated, and socially isolated. Many use drugs or abuse alcohol. Some actively avoid healthcare workers, while many others, living on the margins of society, simply find it too difficult to surmount the numerous, varied obstacles that prevent them from receiving or seeking care.

Unfortunately, there are no well-established formulas that explain how to identify these women or attract them to healthcare providers. Much of the difficulty lies in the extraordinarily varied circumstances of these women. Experience suggests that coercive methods to resolve this issue will result in even more women avoiding care. At the same time, in view of the fact that many of these women view the state with deep suspicion and apprehensiveness, it is difficult to believe that healthcare workers will be able to find and treat these women without assistance from the communities of which these women are a part. Experience also demonstrates that collaboration between government and non-governmental organizations (NGOs) can be an effective strategy for increasing prenatal care coverage of HIV-infected women who become pregnant.

Consideration needs to be given to various ways of promoting such collaboration and, in addition, to methods of providing state support, especially financial support, to non-governmental organizations taking part in the fight against the spreading HIV/AIDS epidemic. For example, the Government might consider establishing a grants program (similar to the AIA program in the United States-see Chapter 4) for conducting "pilot projects" in different regions, aimed at developing practical models of government-NGO cooperation in order to (1) identify pregnant HIV-infected women who are at risk of not receiving prenatal care, (2) counsel these women about the importance of receiving such care, and (3) help to facilitate the delivery of effective care.

In addition, it is necessary to resolve the issue of access to prenatal care for women who lack a local residency permit and/or who are not covered by health insurance. Expenditures for this purpose should be viewed as socially significant, and financing mechanisms need to be established that would ensure that the provision of such services to these women is funded publicly at the appropriate level of government.

Strengthen Measures to Prevent Mother-to-Child Transmission of HIV-Infection

Increasing access to ARV prophylaxis is another key component of programs aimed at preventing abandonment that merits attention.

The Russian Government has achieved significant success in this area in recent years. Considerable scientific and clinical expertise is accumulating. Standard treatment protocols have been developed and disseminated widely. In many regions, particularly those with high prevalence levels of HIV-infection, ARV

prophylaxis is being offered to significant numbers of HIV-infected women who become pregnant. And among those patients receiving treatment, very good results in reducing the rate of MTCT have been achieved.

However, according to the UNICEF Report, in regions with a high prevalence of HIV-infection, less than half of HIV-infected pregnant women receive ARV prophylaxis during pregnancy, and less than two-thirds receive it during delivery. As a result, MTCT rates overall are perhaps 2-3 times higher than they could be if all HIV-infected pregnant women received ARV prophylaxis (even allowing for the women who fail to obtain prenatal care). Extending access to ARV prophylaxis to all pregnant women who are HIV-positive could mean the birth of 700-1,000 fewer HIV-infected children each year.

One of the causes of the still-elevated rates of MTCT is the shortage of antiretroviral drugs, HIV test kits, and local laboratory capacity (needed to evaluate tests and monitor the effectiveness of therapy). ARV prophylaxis at and after delivery ought to be available 100-percent of the time; here the main problem is entirely the lack of the necessary medicines and emergency rapid-test kits which are needed when the delivering mother's HIV status is unknown.

At the present time, as part of the ongoing reform of local self-government, the costs of providing child-birth services are to be funded from municipal budgets, even though many regions do not have the necessary resources. Yet, AIDS surely is a national, not a local problem, and an unfavorable situation in one region ought to be an object of serious concern for all regions. Reducing the frequency of MTCT of HIV-infection should become a government priority. Means must be found to ensure there are sufficient resources in all regions and municipalities for conducting ARV prophylaxis, irrespective of the locality's financial capacity.

Encourage Greater Use of Contraception

The Government should also make a more energetic effort to promote contraception among HIV-infected women who do not wish to become pregnant. The wider utilization of condoms, which also help to prevent the transmission of HIV and other illnesses, should be given much greater publicity and funding.

Strengthen Efforts to Place Abandoned Children in Families

One of the most worrisome findings of this study is the relatively small number of abandoned children born to HIV-infected mothers who are placed with substitute families. To a large degree, this is a result of delayed diagnoses: if all perinatally exposed children were diagnosed at 6 months of age or earlier, the number of children placed with families would surely grow.

Of course, this is not the only step that the Government needs to take in order to increase the number of family placements. Serious measures need to be taken in order to encourage adoption, guardianship, and long-term foster care, including greater financial support for substitute families. In addition, restrictions preventing persons living with HIV from becoming adoptive parents or guardians ought to be reviewed. Also, consideration should be given to instituting "temporary guardianship" for close relatives (grandparents and others) who often serve as the actual care-givers of children whose mothers, while retaining their parental rights, are unwilling to perform this role. This is critical for many families, inasmuch as it would enable the relatives who are actually providing care to receive the government allowances to which the children may be entitled. Strengthened financial incentives for foster parents of HIV-infected children might also be considered.

Provide More Assistance to Families Living with HIV/AIDS

It became apparent in the course of our research that many perinatally exposed children who have not been abandoned live in extremely difficult conditions and are at continued risk of ending up as natural or "social" orphans. These children and their families need help from society and from government: to prevent additional abandonment; and to give the children a better chance to grow up healthy and to become responsible, productive, self-sufficient citizens with their own families.

Providing aid effectively to these children and their families will be challenging. Experience in St. Petersburg (*Tsentr Innovatsiya*) and in other countries shows how varied are the problems and situations of families in need. The most effective organizations seem to be those that are capable of delivering a wide array of services and whose staff have multiple skills and are able to work collaboratively with the parents and other family members whose trust, support, and commitment are essential if the aid is to have its desired impact. In this connection, the most promising model of assistance is that of a locally-based, multi-disciplinary organization working in close cooperation with various local government offices and agencies,

but which is free to set its own agenda and determine its own solutions to the particular set of problems that may exist in a given region. The encouragement of such a model and the support of such organizations could be another component of a Federally-funded grants program of the sort recommended previously as a way to expand the provision of prenatal care to HIV-infected women.

In addition, it is clear that drug and alcohol abuse are the single greatest problem for many of these families and a major reason for the continued vulnerability of their children. There need to be greater opportunities for treatment and rehabilitation, offered to drug- and alcohol-dependent parents. There also needs to be more research and public discussion that would enable full consideration and debate of all positive and negative effects of changes in existing legislative restrictions on the use of so-called "substitution therapy," whereby medicines are administered in order to lessen a patient's craving for narcotic drugs produced by addiction, but without creating heroin's artificial euphoria and other disabling effects. From the standpoint of the child, it is very difficult to understand the rationale for prohibiting a therapy that could prevent some instances of abandonment and that could enable many of the mothers to live more stable, productive lives—and even to prolong their lives, by making antiretroviral drug therapy more feasible.

Improve Epidemiological Surveillance and Analysis

A key task in strengthening the effectiveness of policies aimed at preventing the abandonment of children born to HIV-infected women is to deepen understanding of the dynamics involved in the spread of perinatal HIV-infection. Greater utilization of so-called "second generation" surveillance methods could help in this respect. For example, studies might be organized among women of childbearing age who are at greater risk of infection (commercial sex workers, drug users), in order to analyze behavioral factors that may affect, directly or indirectly, the rate of transmission of HIV-infection from mother-to-child. In addition, "sentinel surveillance sites" might be established for the purpose of estimating the overall prevalence of HIV-infection among pregnant women. Specifically, researchers would designate a number of women's health service clinics located in different regions of the country, which would monitor on a continuing basis the HIV-status of all women attending these facilities, in order to develop an accurate count of the rate of infection among all women of childbearing age living in the areas served by these facilities.

Effective epidemiological surveillance requires the combined efforts of multiple scientific disciplines and an appreciation of many different aspects of individual and population behavior. The only way to improve epidemiological surveillance is through unfettered, open, multidisciplinary, public discussion. To promote such discussion, consideration should be given to issuing a periodical publication containing both official epidemiological data and peer-reviewed analyses and discussions of important issues, including all aspects of perinatal HIV-infection.

The Need for Political Leadership and Will

None of the recommendations presented in this chapter can be implemented without support from the Government, meaning: not only, or even mainly, formal authority and budgetary allocations, but primarily the active, dedicated, and sustained interest and support of political leaders at all levels. For all of these recommendations require significant changes in the behavior of people and institutions.

Experience in Russia and throughout the world demonstrates unequivocally that when it comes to the fight against the spreading HIV/AIDS epidemic, not much can be accomplished in the absence of sufficient political leadership and commitment—that is, without intense political will.

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TRANSATLANTIC | PARTNERS
AGAINST AIDS

Transatlantic Partners Against AIDS (TPAA)

Gazetny per. 5, 3d Floor
125993 Moscow, Russia
Tel.: +7 (095) 510-53-70
Fax: +7 (095) 510-53-71
Website: www.tpaa.ru

Transatlantic Partners Against AIDS (TPAA)

928 Broadway, Suite 800
New York, New York 10010 U.S.A.
Tel.: +1 (212) 228-89-07
Fax: +1 (212) 228-90-63
Website: www.tpaa.net

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