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## KIDS IN CAGES

HIV-orphans – innocent victims of public prejudice

Citizens of a "little land." It's hard to imagine a more underprivileged being than a baby who never knew his/her mother's care. Children left in maternity wards are facing a sorry lot. Very few among them are lucky to find a foster family. But among these who become orphaned at birth there are some who are even sorer – who have practically no hope for the future: abandoned HIV-positive children. Their mothers, who as the rule don't know about their own HIV infection, disappear right after giving birth. And a baby stays behind, and usually is testing positively for HIV antibodies, although this does not mean that a newborn is infected: the anti-bodies can be his mother's. As for the child, his diagnosis becomes clear by the time he is 18 months old. He spends these 18 months in a bed in a hospital box. Nobody holds him, nobody says any loving words. He does not hear any words at all. He is approached with gloves and a protective mask. Because many still believe that HIV can be transmitted through saliva, tears, and bed sheets. The fear of getting infected is stronger than natural compassion for a helpless child. This human cub is more deprived than an abandoned kitten or puppy that still might get petted occasionally.

Lack of communication and affection results in arrested physical, intellectual and emotional development, which become more serious and less reversible as the child grows older. The so called "Mowgli syndrome" develops, only without a wise Bagheera nearby. Many children waiting for their final HIV diagnosis in hospitals, by the age of 18 months don't speak a word, cannot walk, sit at a table, or eat with a spoon.

Abandoned HIV-infected children are truly innocent victims. The question is: whose victims? Of course, as all abandoned children, they are victims of morally deformed and compassionless society, but they are also victims of our ignorance and our prejudice. HIV cannot be transmitted through household or workplace contacts. And it has no effect on intellectual development. Developmental lagging is the result of growing up in isolation, not of the disease.

Even misfortunates need luck. Some HIV-infected children were lucky – those who found themselves at the Clinical Hospital for Infectious Diseases in Ust-Izhora near St.Petersburg. After 270 children were infected with immunodeficiency virus in medical institutions in 1988-89, this hospital started functioning as the children's AIDS clinical center. Its chief physician, professor Yevgeny Voronin says that in 15 years of its existence, it lived through all the stages of HIV-infections' fate. Early in the 90s St.Petersburg newspapers claimed that the hospital must be transferred to Siberia, and doctors sent there to work in drill shifts; they said that if the hospital stays where it is, all neighborhood will develop AIDS in six months. They even succeeded in shutting the hospital down for one day – twenty five hundred signatures were gathered in support of its shut-down and sent to Moscow. But the Health Ministry issued an order to reopen it immediately. Professor Voronin says that there was not a single case of contracting virus from the hospital's patients. It is much easier to contract hepatitis B or C – diseases that are no less dangerous than AIDS.

Today the panic has subsided. Things change gradually. HIV is not something exotic anymore; twenty two thousand people in St.Petersburg live with HIV. And they are no longer marginal individuals. There are cases when, after a child from a regular happy family is unexpectedly diagnosed with HIV, his/her parents are tested, and found infected too. One of them happened to try IV drugs in early youth, never became addicted, and forgot completely about that single experiment. Never even thought that might have contracted HIV. Truly, HIV can affect anyone.

The situation with treating HIV has changed radically in the 15 years since the Ust-Izhora Center was opened. In the early 90s there were no effective drugs, and 10 to 12 children died annually despite all doctors' efforts. With the advent of antiretroviral drugs it became possible to reduce the viral load, and we are talking about extending life expectancy for years. In other words, children will have to enter the adult world. The problem arises, how to prepare them for this world? This problem is especially acute if they are orphans. Of course, the best option is to place them in families. However, no one had been adopted in six years. So the center tries to create a family atmosphere. Children admitted to the Ust-Izhora center frequently suffer from the "Mowgli syndrome." When 18-months old Vanechka was taken out on the street, he screamed and screamed: all his previous short life was limited by the walls of a hospital ward from which he was transferred. Now he gradually begins to communicate with other children (or rather, children communicate with him), but he is still afraid of adults. Katya spent two years in hospital care; she looked like a little animal, but in two months she learned to smile, although constant anxiety remains. Teachers and psychologists work with children at the center. The children are normal, each with his or her individual potential that

has to be developed. Two teachers and four children move to a regular apartment, keep the house, go shopping. Children participate in everything, getting used to a family life instead of a communal one. After a while new foursomes are moved into the apartments.

In our country 10 children are born every day to HIV-infected mothers. A large part of newborn babies are not HIV-infected. Without preventive treatment, the probability of virus transmission from mother to child equals 30 to 50 percent. But if pregnant women undergo appropriate preventive therapy, then the risk of virus transmission goes down to 10 percent (in Western countries even down to 1 or 2 percent). Professor Yevgeny Voronin believes that necessary action must be twofold. First, prenatal treatment must be administered to reduce as much as possible the number of HIV-positive children. Second, children with HIV must be treated properly. Treatment improves all the time, and if seven years ago patients had to take 40 pills per day, now it is just 4 or 5.

But the problem of children's social adaptation remains, especially orphaned children. Any help here would be invaluable, and of course, help from religious organizations. A woman of 50 in Kaliningrad adopted a one year old HIV-infected dystrophic child. She brought him for examination after one year – he was a healthy normal child.

In Ust-Izhora center children are singing:

Beyond the mountains, beyond the woods,  
There is a little land,  
Where animals look with kindly eyes,  
Where life is full of love.

The song sounds heartbreakingly tragic. The little land where orphans felt human affection for the first time, where they saw kindly eyes, is still a hospital. You cannot stay there for life. Will the boundaries of this land ever expand?