VIII. PROGRESS AND IMPEDIMENTS IN ENSURING ORPHANS' RIGHTS

Skeletons come back to life

A striking indictment of the discrimination, neglect and degrading punishment in Russian state orphanages, can be seen in a series of photographs of a few dozen orphans with disabilities, taken from 1994 to 1997.86

Several years ago these children were found in psychoneurological *internaty*, lying with gnarled, limp legs, effectively left to die. Within six months they had flesh on their bones and were out of their beds, smiling, walking and playing.

These were the effects of what began as a volunteer program organized by a group of Russians with no specialized training in the rehabilitation of children with disabilities. Rather they provided basic daily care—feeding, holding, talking, bathing, massaging, and getting needed health services. As the program grew, the group gathered support from western donors and received three in-service training courses from visiting experts from three European countries. They also earned the agreement of government ministries to work with more than 100 disabled orphans in a Moscow psychoneurological *internat*. The results, captured in the photographs at the end of this chapter, are startling.

First there is nine year old Irina, once languishing like a famine victim in a Moscow psychoneurological *internat*, later standing and playing with other children. There is also the emaciated frame of Nina, a little girl tottering on her spindly legs with the help of a steady hand, hardly recognizable a year later. The same can be said of frail little Andrei, once a gruesome sight with his ulcer-covered face, sitting folded up in a large pen for the children; or for Petrushka or Pavel.

The horrors of Russia's “total institutions” came to light in 1994 through the action of Sergei Koloskov, the father of a girl born with Down syndrome, who resisted pressure to abandon his baby and decided to raise her in her family. Shortly afterwards, he founded the Russian Down Syndrome Association for families in similar circumstances, and sought information and assistance from Western donor and disability experts as well as the Russian state association for disabled people.

In 1994, responding to reports of acutely ill orphans in the squalid state institutions in Moscow, Koloskov began to explore the state institutions in Moscow, and came upon a hollow-eyed nine-year-old orphan named Irina in psychoneurological *internat* Number 11. Born with Down syndrome, she had been restrained from the neck down in a cloth sack, and apparently left to die.

Koloskov filmed Irina's deathly figure and his footage aired on Russian television, awakening the audience to a hidden world of neglect known to very few. The haunting images provoked a fiery debate in Russia, and prompted national and international news media to probe the archipelago of locked institutions across Russia. Their exposés revealed considerable variation in the level of care from place to place, but also documented the horrific neglect and punishment. They also spurred Russian volunteers to work with the newly formed Down Syndrome Association, and inspired international volunteers in Moscow such as the International Women's Club, to expand their work in the desperate *internaty* and baby houses.87

Over time, Koloskov felt that his public critique of the state institutions bore few results, and took a more practical approach to seeking ways to work in cooperation with the authorities.88 This led to a formal agreement with government officials to expand the innovative care begun with Irina to include thirty orphans with similar disabilities. He also got the agreement and financial support of the authorities to translate and publish the respected educational series for disabled children called "Small Steps."

A remarkable intervention

The most startling transformation in a group of children has been documented in the work with Irina who was tended to full-time by two volunteers while she received medical treatment in a Moscow hospital in 1995. From that one case, Koloskov gradually recruited several dozen workers through the Russian Orthodox Church to care for as many as 100 orphans in a ward of a large Moscow psychoneurological internat. Although many of the children have serious hereditary conditions such as Down syndrome that may limit their potential overthe long term, they have been spared a lifetime deteriorating in lying-down rooms.89

During our mission to Russia, Human Rights Watch visited the Moscow *internat* where the children in these photographs have come back to life, and saw them at play on tricycles and slides. It was nothing short of incredible; and it was powerful proof of how the systematic neglect in Russian institutions denies children their basic rights.

It is also an alarming sign that an untold number of children are indeed wrongly consigned to bed through misdiagnosis and neglect. It is unclear how many more children with twisted, useless legs could be walking and developing to the maximum of their individual potential.

Showing the pictures at *Internat* X

During our visit to *Internat* X, Human Rights Watch explored the real potential of the orphans there in our initial interview with the staff. We took along a large selection of "before and after" photographs from the Down Syndrome Associations pilot project to show the staff. We were interested in seeking their reaction to the contrast in the children's conditions after the intervention of attentive caretakers, albeit caretakers with no professional expertise in disabilities.

Human Rights Watch found that the older staff *sanitarki* appeared disbelieving and disinterested, while a couple of younger *sanitarki* and one nurse studied the pictures carefully.[90] They noted the children who were emaciated and seemingly deformed in the state *internat*, and later appeared chubby and playful as they crouched on those previously "deformed" legs.[91]

"This one's like ours," said one *sanitarka* pointing to one of the skeletal images. “We have one like this here."[92]

Among the photographs of the orphans were several snapshots taken of Russian adults with Down syndrome, who were playing recorders in a group. Anolder *sanitarka* shook her head and remarked, "They play music, they speak!—these with Down! None of ours can speak."[93]

While studying the photographs, and comparing those children with some of the orphans in their care, one of the staff members of *Internat* X told Human Rights Watch that she thought perhaps ten of their 145 children had potential for a life outside the *internat*.[94]

But the general reaction of the staff at *Internat* X to the photographs indicated that they had accepted their orphans' fate as given, indeed permanent. The idea of encouraging the bedridden children to use their legs and start to crawl was roundly dismissed when one of our Russian contacts mentioned a "great floor mat" that was being used with these transformed orphans. Even though it was clear that the nurse and *sanitarki* were not in a position to make policy changes in the *internat*, we asked if they might be able to use such a floor mat in *Internat X*. Their response was unanimous, as put by one of their number, who said, "Oh no, there's no room for them to crawl, if they started to."[95]

Other progress

Since 1996, when another flurry of media reports revealed the persistent neglect and maltreatment of children in Russian institutions, several of the worst *internaty* have been shut down, and others, such as *Internat* Y, have undergone some physical improvements in their physical surroundings. And recent reports from the Down Syndrome Association suggest that some progress is being made with the Ministry of Social Labor and Ministry of Education in considering better care and education for children with disabilities.[96]

Human Rights Watch also learned of at least two orphanages for school-aged children in St. Petersburg, where the directors were either under criminal investigation or serving a year for charges of abuse brought by advocates of the orphans. In Moscow, too, children's rights activists had succeeded in opening a government investigation into abuse by directors in one orphanage and a residential shelter for children in the suburb of Lubertsy.[97]

Children's rights advocates interviewed by Human Rights Watch in Moscow corroborated the difficulties Alexander Rodin described in trying to remove abusive orphanage directors and staff. One such case involved a residential shelter called "Good Friend," in the Moscow suburb of Lubertsy, where a representative of Rights of the Child investigated reports of deplorable conditions and corporal punishment.[98]

Arriving unannounced on February 18, 1997, Lyubov Kushnir found the children freezing and hungry, as she told Human Rights Watch:

It was not heated at all, and so cold inside that I couldn't take off my heavy coat. Maybe it was three degrees Celsius. I saw bedrooms with no beds at all. All the beds were taken to the gym floor. They were tiny, like kindergarten size, and they were lined up, one next to another in a row. Boys and girls were mixed. I saw two beds with the ends cut off to extend the length for older children. There were no warm blankets—only thin ones. There were about five or six children lying there for the quiet hour, just huddled there, looking pale and scared. They looked about eight or nine years old.

The senior medical nurse told me that she had no medicines and had to go and beg for them. The cook said she had nothing to feed them for dinner, only tea and dried bread.99

Kushnir told Human Rights Watch that despite the apparent poverty of the center, 1.5 billion rubles (about $300,000) had been allocated four years ago for a major renovation of the building.100

Eventually, the Russian procuracy (prosecutor) commenced an investigation and according to Kushnir, the director was charged in September 1997 with exploitation, humiliation, cruelty to children, and financial wrongdoing.101

But by February 1998, Kushnir was informed by friends of the director that the case had been closed in January. At that time, children's rights advocates told Human Rights Watch that due to the director's relations with the Ministry of Education's Moscow Committee, the local branch of the Education Ministry in Lubertsy feared that they could lose their jobs if they did not accept the decision.102

Kushnir also reported that the director's supporters tried to intimidate her by threatening to bring some kind of action against her nongovernmental organization Rights of the Child. 103

Through her organization, Kushnir nevertheless appealed to the procuracy and the case was re-opened. In the end, the children's advocates prevailed, and the director was fired.104

Further progress was reported by the Moscow-based NGO Rights of the Child, which together with several independent child development specialists and psychiatrists, has engaged the Russian government to consider their proposal for an independent citizens' oversight committee to monitor children's rights in the institutions.

But as the above account illustrates, progress is slow, tainted with official intimidation, and advocates for children's rights told us that they still face several systemic obstacles.

Russian government reaction to critics

In general, the Russian authorities have reacted to the critiques of their orphanages by blocking access to the institutions; punishing or threatening to fire workers if they speak about abuses; and, in some instances, promoting those who are responsible for the wrongdoing.

Senior officials of the three ministries charged with maintaining the orphanages have consistently rejected requests from human rights groups and child welfare experts to visit the particularly inhumane psychoneurological *internaty* run by the Ministry of Labor and Social Development.105

Nor do they easily share information that should be in the public domain, according to Dr. Anatoly Severny:

When I went to the Ministry of Social Welfare and asked for data on *internaty*, they refused me and said I needed special permission from the deputy minister. I sent an official request to the Deputy Minister, and there's been no reply for three weeks. 106

Dr. Severny further described to Human Rights Watch how high-level officials discriminate against children deemed to be "untrainable," in blocking proposals to shift orphans to institutions for more appropriate care:

One year ago we started to try to get the mentally disabled children transferred from the Ministry of Labor to the Ministry of Health, so they would get better treatment. But the Ministry of Health does not want these children. We called press conferences. We went to the Duma (lower house of Parliament). But everybody said these children are not trainable; they don't need to be treated. What's the use of transferring them to the Ministry of Health?107

High risk for Russian orphans

Among the greatest perils facing orphans in Russia is their entry into society at large. Their lack of preparation for life on their own was a frequent concern of experts and orphanage staff interviewed by Human Rights Watch. UNICEF, too, calls the children who leave state care the "most vulnerable group of children.108

One staff teacher of Moscow Orphanage A—herself raised in a *dyetskii dom*—poignantly summarized what Human Rights Watch heard again and again:

The most dreadful thing about the whole system of education and training is that the orphans are well equipped in electronic things, decent furniture, and a little spending money. But they're not prepared for future life. They don't know how to *make* money, even how to make *tea*! Look at the official statistics.109

The statistics are grim indeed. According to the Russian Procuracy General, some 15,000 children leave state *dyetskiye doma* every year. Within several years, 5,000 will be unemployed; 6,000 will be homeless; 3,000 will have criminal records; and 1,500 will commit suicide.110

When orphans leave the state institutions at eighteen years of age, they receive a lump sum—

about seven million rubles in St. Petersburg—which is barely enough to buy the furniture for a single room.111 We also heard reports from the staff of Education Ministry orphanages who claimed that these children were also victims of financial corruption:

In principle, each child should have a private bank account. But in practice, really few of them get one. Also they're supposed to have an apartment where they are officially registered if they have a family member or guardian but who knows what they do with the apartment.

For example, the apartment where a boy named Maxim A. was registered had been occupied for several years by a state organization which used it for storage. That's not the only case. Also some are taken by Moscow and sold off.112

The same teacher from Orphanage A in Moscow cited another case he knew of a girl whose family was allegedly misusing the apartment that was legally hers:

Take the case of Vika Z. Her aunt rents out the apartment and all the money she gets for it she doesn't give to Vika. It's Vika's money, and it should go to her bank account for when she gets out of the orphanage. 113

But the problems for the orphans start earlier, in the socialization they receive in the institution, and the second-class treatment they report that they receive in the public schools they attend. According to another teacher from Moscow Orphanage A, himself a product of a *dyetskii dom*, the children do not receive the same attention and encouragement from the public school teachers as children from families:

They go to regular public schools, but they're not welcomed there. In the regular school the teachers don't know the mentality of this place or the atmosphere of the place where they grow up. Also, the other kids try to exclude them. For example, instead of studying the whole nine classes for a diploma, the orphans often study only up through the sixth year. Only one of the girls in our group finished the standard nine years.114

Conclusion

Legion are the difficulties facing abandoned children in Russian state institutions. For those who are not doomed to a life in a locked asylum, the full effects of their discrimination still awaits them when they leave the sheltered and stunting world of the orphanage.

While certain progress has been made, we are aware of the views we heard again and again, from Russians and international experts deeply involved in the care of abandoned children, summarized below by this experienced volunteer:

It's attitude, plus no feeling at all of responsibility by anyone who looks after them. I know this sounds extreme, but I've seen it again and again. It's also ignorance. The most horrific thing, you can meet officials of the Ministry of Health, or the Ministry of Social Welfare, who've actually seen how children can be treated and taught to walk, and learn. Officials who've been to other countries.

One of these is the head of the psycho-neurological *internaty* for Moscow. But under her care, children are in straitjackets, little skeletons like in Romania. The first time I was at one of the *internaty* there was a child in cloth bag and another in a straitjacket. And she [the official] railed on about how the boy has to be tied up or else he'll swallow his fist.

"So we are not talking about money at all. We are talking about no conscience, no soul. And if she is not responsible for these children, then who is?"

86 The photographs, appearing at the end of this chapter, are from the collection of Sergei Koloskov, president of the Down Syndrome Association (DSA), and are part of a joint project between the DSA and the European-based nongovernmental organization International Catholic Children's Bureau.

87 Human Rights Watch interview, volunteer, December 20, 1998. Over the years, new charities, notably Action for Russia's Children (ARC) and Downside Up, have provided services to a range of institutions.

88 Human RightsWatch interview, Sergei Koloskov, November 13, 1998.

89 Human Rights Watch interview, Moscow psychiatrist, Dr. Tatiana Moroz, February 12, 1998.

90 Human Rights Watch interview, Iliana Danilova, Alla Sergeyeva, Lyuba Fokina, February 15, 1998.

91 Human Rights Watch interview, Alla Sergeyeva, February 15, 1998.

92 Ibid.

93 Human Rights Watch interview, *internat sanitarka*, February 15, 1998.

94 Human Rights Watch interview, Iliana Danilova, February 15, 1998.

95 Human Rights Watch interview, Iliana Danilova, Alla Sergeyeva, February 15, 1998.

96 Human Rights Watch interview, Sergei Koloskov, October 23,1998.

97 Human Rights Watch interview, Lyuba Kushnir, February 23, 1998.

98 Human Rights Watch interview, February 16, 1998. Although a residential shelter is a more temporary facility for the burgeoning population of street children, "Good Friend" operates under the supervision of the Ministry of Education and should therefore be subject to the same scrutiny accorded other custodial institutions. Russian children's advocates regard this case as a good example of corruption.

99 Human Rights Watch interview, February 23, 1998.

100 Ibid. Exchange rate as of February 1998.

101 Ibid.

102 Ibid.

103 Human Rights Watch interview, Lyuba Kushnir, September 30, 1998.

104 Ibid.

105 Human Rights Watch interview, Boris Altshuler, February 16, 1998; Dr. Anatoly Severny, February 12, 1998.

106 Human Rights Watch interview, February 12, 1998.

107 Ibid.

108 UNICEF, *Children at Risk*, p. 89.

109 Human Rights Watch interview, teacher, Orphanage A, February 20, 1998.

110 Cited in UNICEF, *Children at Risk*, p. 89.

111 Human Rights Watch interview, Yuri T., St. Petersburg, February 27, 1998.

112 Human Rights Watch interview, teacher, Orphanage A, February 20, 1998. The misallocation of apartments intended for orphans leaving state custodial institutions was corroborated by an attorney specializing in juvenile law in a Human Rights Watch interview, October 14, 1998.

113 Ibid.

114 Human Rights Watch interview with teacher, Orphanage A, Moscow, February 20, 1998.