




HUMAN
RIGHTS
WATCH

ABANDONED BY THE STATE

Violence, Neglect, and Isolation for Children with Disabilities
in Russian Orphanages

SUMMARY AND KEY RECOMMENDATIONS



Children in specialized orphanages for young children in central Russia often spend their days with little to no attention from staff, who often lack training on how to engage children with disabilities in educational or recreational activities.

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The staff used to hit me and drag me by the hair. They gave me pills to calm me down.

— NASTIA Y., A 19-YEAR-OLD WOMAN WITH A DEVELOPMENTAL DISABILITY, DESCRIBING THE TREATMENT OF STAFF IN AN ORPHANAGE FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN PSKOV REGION, WHERE SHE LIVED FROM 1998 TO 2011

Every child with a disability in Russia has a significant chance of ending up in a state-run orphanage. Nearly 30 percent of all Russian children with disabilities live separately from their families and communities in closed institutions. These children have a range of impairments, including physical disabilities such as limited mobility, blindness, and deafness; developmental disabilities such as Down's syndrome; and psychosocial disabilities such as depression, among others. Children with disabilities in state orphanages may be subject to serious abuses and neglect that severely impede their physical, emotional, and intellectual growth.



Nikita P., a 10-year-old boy, in his crib in a Sverdlovsk region orphanage for children with developmental disabilities. Children segregated into separate “lying-down” rooms spend the overwhelming majority of their days confined to cribs or beds.
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Children with disabilities may be overrepresented in institutional care. On international children’s rights nongovernmental organization (NGO) estimates that approximately 45 percent of children living in state institutions have some form of disability, despite the fact that children with disabilities account for only 2 to 5 percent of Russia’s total child population. The Russian government’s failure to ensure meaningful alternatives for these children means that many children with disabilities spend their childhoods within the walls of institutions, never enjoying a family home, attending school, or playing outside like other children.

This report is based on visits by Human Rights Watch researchers to 10 orphanages in 6 regions of Russia, as well as on more than 200 interviews with parents, children, and young people currently and formerly living in institutions in these regions in addition to 2 other regions of Russia. Children described how orphanage staff beat them, used physical restraints to tie them to furniture, or gave them powerful sedatives in efforts to control behavior that staff deemed undesirable. Staff also forcibly isolated children, denied them contact with their relatives, and sometimes forced them to undergo psychiatric hospitalization as punishment.

Many children also experienced poor nutrition and lack of medical care and rehabilitation, resulting in some cases in severely stunted growth and lack of normal physical development. Human Rights Watch determined that the combination of these practices can constitute inhuman and degrading treatment. Children with disabilities living in orphanages also had little or no access to education, recreation, and play.

Children with certain types of disabilities, typically those who cannot walk or talk, are confined to so-called “lying-down” rooms in separate wards, where staff force them to remain in cribs for almost their entire lives. Human Rights Watch documented particularly severe forms of neglect in “lying-down” rooms in the institutions it researched. The practice of keeping children with certain types of disabilities in such conditions is discriminatory, inhumane and degrading, and it should be abolished.

Research by the United Nations Children’s Fund (UNICEF) and others has demonstrated that institutionalization has serious consequences for children’s physical, cognitive, and emotional development, and that the violence children may experience in institutions can lead to severe developmental delays, various disabilities, irreversible psychological harm, and increased rates of suicide and criminal activity. UNICEF has urged governments throughout Central and Eastern Europe and Central Asia to stop sending children under the age of 3, including children with disabilities, to institutions.

While Russia lacks comprehensive and clear statistics on children in state institutions or foster care, experts estimate that the overwhelming majority of these children have at least one living parent. Russia’s high rate of institutionalization of

children with disabilities results from a lack of government and state-supported services, such as inclusive education, accessible rehabilitation, and other support that would make it feasible for children’s families to raise them. In addition, many parents face pressure from healthcare workers to relinquish children with disabilities to state care, including at birth. Human Rights Watch documented a number of cases in which medical staff claimed, falsely, that children with certain types of disabilities had no potential to develop intellectually or emotionally and would pose a burden with which parents will be unable to cope. In all of these cases, the children raised in their families had far exceeded any expectations.

Children with disabilities who enter institutions at a young age are unlikely to return to their birth families as a result of the practice of local-level state commissions to recommend continued institutionalization of children. The Russian government has failed to adequately support and facilitate adoption and fostering of children with disabilities, although these types of programs formally exist. As a result, when children with disabilities turn 18 and age out of orphanages, they are overwhelmingly placed in state institutions for adults with disabilities. Staff in many orphanages also fail to provide training and practical knowledge that would give children the skills they need to live independently once they become adults.

While in orphanages, children with disabilities may be subject to serious violence, neglect, and threats. For example, Human Rights Watch documented the use of sedatives to restrain children deemed to be too “active” in 8 out of the 10 institutions it visited in the course of researching this report. Twenty-five year-old Andrei M., a young man with a developmental disability who lived in an orphanage in Pskov region until 2008, told Human Rights Watch, “They constantly gave us injections, and then they sent us to the bedroom so that we would sleep.”

Human Rights Watch spoke with many orphanage staff who expressed a desire to support children’s maximal development and who worked hard to do so with the information and resources at their disposal. Some of these staff were also those who used practices such as physical and chemical restraints, for example. The findings below are presented with the understanding that well-intentioned staff often engage in unacceptable childrearing methods because they lack information, such as training in nonviolent disciplinary methods, as well as resources, such as additional personnel to help them care for large numbers of children.

Children with disabilities living in state institutions may also face various forms of neglect, including lack of access to adequate nutrition, health care and rehabilitation, play and recreation, attention from caregivers, and education. For example, Olga V., a pediatrician at a Sverdlovsk region orphanage for children with developmental disabilities, stated that not all children in the orphanage go to school, including 150 children in “lying-down” rooms who she claimed were



Roman K., 18, (left) and Lyuba P., 15, in a “lying-down” ward of an orphanage for children with disabilities in northwest Russia. Roman K. was awaiting transfer to an institution for adults with disabilities. A pediatrician specializing in the health of children with disabilities told Human Rights Watch that, based on photographs, both Roman K. and Lyuba P. appeared significantly underdeveloped for their ages, a possible result of inadequate nutrition, stimulation, and health care.

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“uneducable” (neobuchaemy) – an outdated diagnosis that state doctors and institution staff continue to assign to some children. In the same orphanage, another pediatrician stated that rather than select food appropriate for children’s ages and health needs, staff “grind up whatever we have and use tubes to feed the ones who can’t feed themselves.”

As a result of violence and neglect, children with disabilities in state institutions can be severely physically and cognitively underdeveloped for their ages. Nina B., an independent, Moscow-based pediatrician specializing in the health of children with disabilities, told Human Rights Watch that children from orphanages often become atrophied due to lack of stimulation, movement, and access to rehabilitation services.

Children with disabilities living in state institutions also face numerous obstacles to adoption and fostering, including lack of government mechanisms to actively locate foster and adoptive parents for children with disabilities; lack of support for adoptive and foster families of children with disabilities; and some state officials’ negative attitudes towards children with disabilities and their active attempts to dissuade parents

from adopting or fostering these children on the basis that they will be unable to care for them.

The Russian federal government has in recent years developed several policies that include important measures to end institutionalization and provide better alternatives for children with disabilities and their families. For example, the government formulated the National Action Strategy in the Interests of Children for 2012-2017, which aims to create government support services that would enable children with disabilities to remain in their birth families, return children with disabilities who live in institutions to their birth families, and increase the number of Russian regions that do not use any form of institutional care for orphans. The government also established a foundation to finance projects by regional governments and NGOs in certain priority areas, including prevention of child abandonment and social inclusion of children with disabilities.

However, these well-intentioned policies lack clear federal plans for implementation and monitoring. As such, they fail to adequately address the widespread practice of institutionalization of children with disabilities and to create sufficient

Sveta L., a 13-year-old girl in her crib in a “lying-down” room of an orphanage for children with disabilities in northwest Russia. A pediatrician specializing in the health of children with disabilities told Human Rights Watch that, based on photographs, Sveta L. appeared significantly underdeveloped for her age, a possible result of lack of stimulation and a well-rounded diet.

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Natasha K. lives in an orphanage for children with disabilities in northwest Russia, in a room for girls between the ages of 12 and 18. Lacking training and other resources to engage Natasha K. using nonviolent means, staff bound Natasha K.'s hands behind her back in order to prevent her from scratching at her eyes.
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meaningful alternatives for children with disabilities and their families.

In May 2014 the Russian government also passed a resolution that establishes orphanages as temporary institutions whose primary purpose is to place children in families and mandates that orphanages protect children's rights to health care, nutrition, and information about their rights, among other fundamental rights guaranteed under the UN Convention on the Rights of the Child (CRC). While the resolution contains important protections for all children living in state institutions, Human Rights Watch is concerned that several of its articles may segregate children with disabilities living in state institutions from their peers without disabilities and that the resolution does not give sufficient attention to the needs of children with disabilities with regard to adoption, fostering, and access to information on their rights.

Russia has a robust civil society, including many groups that advocate on behalf of children with disabilities and provide services to both children in institutions and children with disabilities and their families outside of institutions. For example, several groups in Moscow and other Russian cities raise awareness about the human rights and dignity of people



with disabilities, provide parents of newborns with disabilities with information on services available to these children in the community, and provide services such as support groups to parents of children with disabilities.

With regard to disability rights, the Russian government has taken steps to create more accessible infrastructure and community-based services for all persons with disabilities. For example, in May 2014 the Russian State Duma accepted in their first reading a set of amendments that include a prohibition against disability-based discrimination and an expanded list of changes to be made so that public facilities and services are accessible.

While these initiatives are important, Russia has a long way to go to enable children with disabilities to grow up in their communities and participate in community life. Most importantly, Human Rights Watch has found that children with disabilities and their families have felt the effects of the government measures to a very limited extent. Parents continue to give up their children to state care with little or no information about their children's rights and developmental potential or about community-based services that are available to help them raise their children.

Children in a specialized orphanage for young children with disabilities in central Russia. Staff sometimes bound children's arms to their torsos in order to prevent them from scratching at their eyes or from leaving their high chairs or cribs.

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Human Rights Watch documented a number of cases in which medical staff claimed, falsely, that children with certain types of disabilities had no potential to develop intellectually or emotionally and would pose a burden with which parents will be unable to cope. In all of these cases, the children raised in their families had far exceeded any expectations.



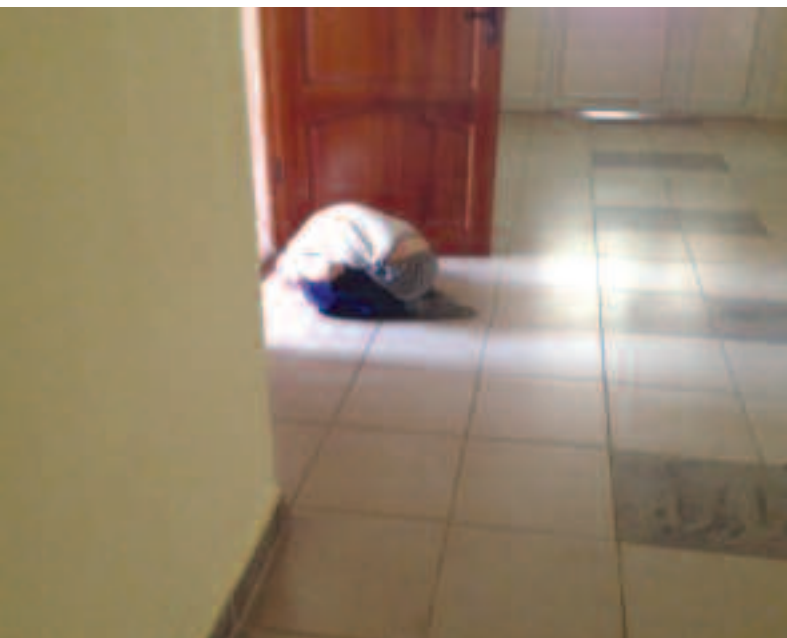
Dasha, a girl with Down syndrome, shortly after her first birthday in Moscow in 2000. This photo was taken during Dasha's first days at home with her family to whom she returned after spending the first year of her life in a local orphanage. © Private



Dasha, who spent her first year of her life in an orphanage, reading at home in Moscow with her younger sister Anya. © Private



Dasha, at home in Moscow with her parents, where she enjoys taking care of her elderly grandmother and younger sister, also in the photo. © Private



A boy crouches on the floor of a state orphanage for children with disabilities, Sverdlovsk region.

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In order to ensure protection of the rights of children with disabilities in Russia and to comply with its international human rights obligations, the government should immediately adopt a zero tolerance policy for violence, ill-treatment, isolation, and neglect of children with disabilities living in state institutions and guarantee children’s rights to food, education, and play. In addition, the government should accelerate and expand initiatives to prevent healthcare workers from pressuring parents of children with disabilities to relinquish care to institutions. In cases where children are orphaned or living without parental care, the government should ensure that institutionalization is used only in the short term, in emergency situations, to prevent the separation of siblings, and when necessary and constructive for the child and in his or her best interest.

In the long term, Russia should take concrete steps to end the institutionalization of children, especially infants separated from their parents, with extremely limited exceptions, as described above.

Until the government acts, it will needlessly continue to consign these children to lifetimes within four walls, isolated from their families and communities, and robbed of the opportunities available to other children.



A group of girls, ages 10 to 15, in an orphanage for children with disabilities in northwest Russia. Many children in “specialized” orphanages spend their days seated in rooms with minimal attention from staff, who often lack training and other resources to engage children in activities appropriate to their ages and disabilities.

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(above) The wall surrounding a psychoneurological internat, or a closed institution for adults with disabilities. For the vast majority of children with disabilities living in state orphanages, entry into psychoneurological internats at age 18 is a near certainty.

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(opposite) Wheelchairs stacked on the upper balconies of an institution for adults with disabilities in northwest Russia. Staff told Human Rights Watch that the institution saves rehabilitation equipment such as wheelchairs in order to account for them during government audits. Residents of this institution who could use these wheelchairs are instead confined to beds all day due to staff's conviction that they are too sick to engage in activities.

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TO THE RUSSIAN GOVERNMENT, INCLUDING THE MINISTRIES OF LABOR AND SOCIAL PROTECTION, HEALTH, AND EDUCATION

IMMEDIATELY

- Establish a zero tolerance policy for state children’s institution staff who beat, humiliate, or insult children.
- End the use of physical restraints, sedatives, forced isolation, and forced psychiatric treatment as means of managing or disciplining children in care.
- Abolish the practice of confining children with certain types of disabilities to “lying-down” rooms.
- Ensure that parents and children are able to contact and visit with one another at will, with no adverse consequences to children’s well-being.
- Guarantee children with disabilities living in state institutions access to inclusive education, adequate nutrition and water, health care, rehabilitation, and play.
- Establish robust monitoring mechanisms and systems of redress accessible to children with disabilities.
- Ensure institutionalization is used only in the short term, in emergency situations, to prevent the separation of siblings, when necessary and constructive for the child, and in his or her best interest, including by:
 - o Providing information to expectant parents and healthcare workers who serve new parents on the rights and dignity of children with disabilities;
 - o Providing parents of children with disabilities telephone numbers and addresses of community-based support services such as early education programs for children with disabilities.

MEDIUM TO LONG-TERM

- Establish a time-bound plan to end the institutionalization of children, especially infants separated from their parents, with extremely limited exceptions. This plan should:
 - o Ensure that state financing for formal care of children with disabilities privileges family-based care options;
 - o Include measures to return children with disabilities to their birth families and ensure that families have adequate support to care for these children;
 - o Include measures to actively encourage adoption and fostering of children with disabilities.
- Fully realize efforts to make Russian communities accessible and inclusive to all persons with disabilities, including children with disabilities.

TO RUSSIA’S INTERNATIONAL PARTNERS, INCLUDING THE EUROPEAN UNION AND ITS MEMBER STATES, THE UNITED NATIONS CHILDREN’S FUND (UNICEF), THE WORLD BANK AND OTHER INTERNATIONAL FINANCIAL INSTITUTIONS, AND ALL DONORS – GOVERNMENTAL AND NONGOVERNMENTAL – ENGAGED IN ASSISTANCE PROGRAMS WITH RUSSIA IN THE CONTEXT OF MULTILATERAL AND BILATERAL FUNDING

- Earmark financial and other forms of support and assistance toward support services for families of young children with disabilities and prevention of child abandonment, as well as toward family reunification and other forms of family-based care for children with disabilities separated from their biological families.

ABANDONED BY THE STATE

Violence, Neglect, and Isolation for Children with Disabilities in Russian Orphanages

Nearly 30 percent of all Russian children with disabilities live in state-run orphanages, separated from their families and communities. Children with disabilities living in orphanages may face serious abuse and neglect that severely impede their physical and intellectual growth. Many children with disabilities are institutionalized because doctors tell their parents that children lack prospects for development or that parents cannot care for them.

In recent years the Russian government has developed policies to end this form of institutionalization and offer more community-based services to children with disabilities and their parents in order to facilitate children living with their families. However, these policies do not specify mechanisms for implementation and monitoring.

Abandoned by the State is based on research in 10 Russian orphanages for children with disabilities and over 200 interviews with currently and formerly institutionalized children and young people with disabilities and their parents, children's rights advocates, and orphanage staff. Children with disabilities living in state orphanages face a range of human rights abuses. These include beatings and the use of abusive physical restraints, sedatives, and psychiatric hospitalization to control and punish children; isolation, insults, and denial of contact with family members, among other forms of psychological violence; and lack of access to education, play, adequate nutrition, and health care for children.

Human Rights Watch calls on the Russian government to immediately end violence and neglect towards children living in institutions. Russia should also reduce the number of children in institutions by transitioning them out of orphanages into birth or foster families. In the long term, Russia should make a plan to end institutionalization of children with disabilities so that children can be placed in state care only in limited circumstances that serve their best interest and in compliance with international human rights law.



A child in a Russian state orphanage for children with disabilities.

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