Human Rights Watch Submission to the United Nations Committee on the Rights of the Child on Russia

November 2013

This memorandum, submitted to the United Nations Committee on the Rights of the Child ("the Committee") in advance of its upcoming periodic review of Russia, highlights areas of concern we hope will inform the Committee's consideration of the Russian government's ("the government") compliance with the Convention on the Rights of the Child ("the Convention"). It contains information on Russia's treatment of children with disabilities and lesbian, gay, bisexual, and transgender (LGBT) children that are inconsistent with articles 2, 9, 13, 16, 18, 23, 28, and 29 of the Convention and highlights concrete steps the Russian government should be asked to take to address the concerns identified.

This submission is based on ongoing monitoring of the government's respect for the rights of people with disabilities, including children with disabilities, and LGBT people over the past year. Human Rights Watch has produced a report entitled *Barriers Everywhere*, describing its research findings on barriers to accessibility for people with disabilities in Russia. For a fuller analysis, please see the following Human Rights Watch publications: *Barriers Everywhere: Lack of Accessibility for People with Disabilities in Russia*; "In Russia, Every Day Should Be National Coming Out Day"; "Russia: Use Leadership to Repeal Discriminatory Propaganda Law"; and "Anti-gay law shames Putin's Russia".

Human Rights Watch considers the Committee's upcoming review of Russia to be critical to sustaining the international attention and pressure we believe are essential to ensure that the rights of vulnerable children, such as children with disabilities and LGBT children, are fully respected in Russia. We are pleased to note in the Committee's List of Issues drawn up for Russia questions that touch upon these issues, including regarding the concept of inclusive education referred to in the Law on Education of January 2013; the types of

assistance and support provided to families with children with disabilities; and measures in place to ensure protection from discrimination against LGBT children.

Children with Disabilities (Convention articles 2, 9, 18, 23, 28, 29)

In 2012 and 2013 Human Rights Watch carried out interviews with people with disabilities across six cities in four regions of Russia, including with 21 children with disabilities as well as with many parents of children with disabilities. Human Rights Watch also spoke with 20 representatives of disabled persons organizations and nongovernmental organizations (NGOs) about obstacles that people with disabilities face to participating in their communities. The following is a summary of several concerns that Human Rights Watch wishes to highlight.

Inclusive Education (Convention articles 2, 23, 28, 29)

According to the Russian disability rights NGO Perspektiva, only 250,000 (or 42 percent) of 590,000 children registered as having disabilities in Russia receive any education. Of these 250,000 children, approximately 56 percent study in mainstream schools; 16 percent study at home; and 28 percent study in specialized schools for children with disabilities. The remaining 340,000 children do not receive education. Reasons for lack of access to education include children's location in closed institutions that offer no education whatsoever, a lack of specialized schools in children's locales, architectural inaccessibility of schools, parents' lack of knowledge of their children's rights, and government authorities' labeling of some children with disabilities as "ineducable" or incapable of studying.[1]

Some children with disabilities and their parents reported to Human Rights Watch that they preferred specialized schools to inclusive schools because teachers in the former were better able to adjust their methods to children's learning needs.[2] However, in some cases children with disabilities attended specialized schools because their parents lacked information on their children's rights to inclusive education or because children with

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[1] "Education of the disabled in Russia [Образование инвалидов в России]," 2010, Perspektiva, http://perspektiva-inva.ru/protec-rights/articles/vw-840/, accessed October 28, 2013.

[2] For example, Human Rights Watch interviews with Svetlana Fadaeva, Moscow, February 15, 2013; and Marina, Ulan-Ude, December 13, 2012.

disabilities were denied admission or reasonable accommodations in mainstream schools.[3] The obstacles children with disabilities face to accessing mainstream schools violate their right to access education on the basis of equal opportunity.

Russia is also party to the Convention on the Rights of Persons with Disabilities (CRPD), which grants children the right to an inclusive primary and secondary education. The CRPD states that children should not be excluded from the general education system on the basis of disability.[4] To implement inclusive education, schools in the general system must provide suitable equipment and teaching materials for persons with disabilities; adopt teaching methods and curricula that embrace the needs of all children; train all teachers to teach in an inclusive classroom; "provide a range of support that meets the diverse needs of all students, including students with disabilities"; and facilitate the learning of Braille and sign language so that children who are blind, deaf, or deaf-blind can access education and communicate. The above mentioned obligations are ones of progressive realization.[5]

Human Rights Watch research has found that children with disabilities in Russia face multiple obstacles to gaining admission to and physically accessing schools in the general school system, and sometimes to schools in the specialized system as well. These obstacles include: lack of accessible wheelchair ramps and elevators; lack of reasonable accommodations for children with physical, sensory, and developmental disabilities; teachers' lack of knowledge on how to adapt their curriculum and methods to the learning needs of children with disabilities; and the refusal of teachers and some school directors to enroll children with disabilities in their schools. In some instances, teachers and school administrators claimed that the children's appearances would frighten other children or that they would be unable to understand the subject matter.

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[3] For example, Human Rights Watch interviews with Maria, Orekhovo-Zuyevo, December 7, 2012; and Maksim, Moscow, December 18, 2012.

[4] Convention on the Rights of Persons with Disabilities (CRPD), adopted December 13, 2006, G.A. Res. 61/106, annex, 61 U.N. GAOR Supp. (No. 49) at 65, U.N. Doc. A/RES/61/106/Annex II, entered into force May 3, 2008, ratified by Russia on September 25, 2012, art. 24.

[5] Committee on the Rights of Persons with Disabilities, "From provisions to practice: implementing the convention," Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities, 2007, http://www.ipu.org/PDF/publications/disabilities-e.pdf, accessed November 8, 2013.

Until July 2013 the Federal Law "On the Social Protection of the Disabled in the Russian Federation" granted regional government authorities discretion to recommend whether individual children with disabilities attend mass schools or specialized schools, or study at home.[6] The revised federal law states, "If it is impossible for disabled children to study in general education programs, educational management authorities, at the agreement of parents, will organize home study for disabled children." The law did not state what "impossible" meant. Parents are responsible for submitting a written petition for this arrangement and medical professionals are responsible for approving it.[7] It remains unclear what discretion is granted to local Bureaus of Medical-Social Expertise (commissions of doctors, healthcare and rehabilitation professionals, and a social worker) to recommend home study; the criteria they use to make recommendations and/or evaluate parents' petitions; and the role of educational management authorities and the Bureaus of Medical-Social Expertise in providing information to parents and children on children's right to education.

Children with disabilities and their parents have the right under Russian law to decline government recommendations about the type of education children should receive. However, in the absence of information about their children's rights to an education, many parents with whom Human Rights Watch spoke understood recommendations from government officials as binding orders.[8] For example, Maria, the mother of a five-year-old girl with cerebral palsy in the Moscow region, told Human Rights Watch that in 2011 a commission from the Bureau of Medical-Social Expertise recommended that her daughter attend a specialized school, despite Maria's insistence that her daughter is capable of studying at a mainstream kindergarten. One of the doctors on the commission warned Maria that children at the mainstream kindergarten would "trample" her daughter. Believing that the commission's recommendation was an order meant to protect her daughter's safety, Maria sought to enroll her daughter in a specialized kindergarten.

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[6] Federal Law "On the Social Protection of the Disabled in the Russian Federation," No. 122-FZ, 2013, art. 18, para. 4.

[7] Federal Law "On the Social Protection of the Disabled," No. 181-FZ, 2013, art. 19.

[8] For example, Human Rights Watch interviews with Tatiana T., disability rights activist and parent of a man with a disability, Orekhovo-Zuyevo, December 7, 2012; Maria, Orekhovo-Zuyevo, December 7, 2012; and Inna (pseudonym), St. Petersburg, February 26, 2013.

Many of the 140,000 children cited above who study in mainstream schools may in fact be receiving an inferior education. Some public kindergartens and primary schools in Russia include a system called a *lekoteka*, in which a child with a disability and a parent attend kindergarten three or four days a week, for three hours per day, in separate groups. Though *lekotekas* are meant to help parents facilitate their children's development, this system of segregating children with disabilities and limiting the amount of time that children with disabilities can spend in school constitutes discrimination.

Aside from immediate obstacles to attending schools in the general education system, children with disabilities and their parents reported to Human Rights Watch that their cities lack sufficient accommodations for children to easily leave their homes and travel to school. People interviewed by Human Rights Watch reported a lack of sufficient wheelchair accessible buses; difficulty accessing the metro in St. Petersburg and Moscow since very few stations are wheelchair accessible; and inconsistent or limited clearing of ice and snow from pedestrian walkways and school parking lots, making it difficult and dangerous for children with physical or sensory disabilities in particular to go to school.

For example, in November 2011 a 10 year-old boy with cerebral palsy fell and broke his arm on the ice in the parking lot of his Moscow region mainstream school.[9] According to a disability rights activist and two parents of children with disabilities residing in the town, the school parking lot is not always clear of ice and snow in the winter. Furthermore, the school lacks both a ramp at its entrance and an elevator to allow students with physical disabilities to safely attend classes.[10] Moreover, in several cities where we conducted research, young people with physical disabilities with whom Human Rights Watch spoke live in apartment buildings without elevators and whose entrances lack wheelchair ramps, which make it difficult and in some cases, dangerous for them to enter and leave their homes, and which they stated was a decisive factor preventing them from attending school as children.[11] These obstacles prevent these children from enjoying their right to education and to a full and decent life. They also constitute violations of Russian federal law, which

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[9] Human Rights Watch interview with Sergei (pseudonym), Orekhovo-Zuyevo, December 7, 2012.

[10] Human Rights Watch interviews with Tatiana T., disability rights activist; Svetlana, parent of a child with a disability; and Maria, parent of a child with a disability, Orekhovo-Zuyevo, December 7, 2012.

[11] Human Rights Watch interviews with Maria (pseudonym), Sochi, February 10, 2013; Nikolai, Orekhovo-Zuyevo, December 7, 2012; and Yulia, Ulan-Ude, December 13, 2012.

mandates that all infrastructure be accessible to people with disabilities, including schools and public housing, and regardless of whether buildings are private or government owned.[12]

The Russian law "On Education in the Russian Federation," which came into force in September 2013, places a premium on inclusive education. Inclusive education is defined as the "provision of equal access to education for all students, given a diversity of special educational needs and individual capabilities."[13] The law requires regional and city-level governments to "create the necessary conditions for quality education without discrimination towards persons with disabilities," using appropriate pedagogical and communication methods and directed towards the "social development" of children with disabilities.[14] This law does not set minimum inclusive education standards regulating factors such as specialized teacher education, reasonable accommodations, and other infrastructural and curricular changes to ensure that inclusive education is made available to all children in practice. According to Maria Perfilieva, manager of education projects at the disability rights NGO Perspektiva, federal lawmakers are currently developing concrete implementation standards for inclusive education. However, Perfilieva told Human Rights Watch that she understands the standards as currently drafted recommend curricular and infrastructural modifications only for specialized schools, neglecting to ensure the right of children with disabilities to access schools in the general education system.[15]

Human Rights Watch hopes to see the Committee use its upcoming review of Russia to request information on the following specific concerns, which at present seriously undermine the rights of children with disabilities:

1. How many children with disabilities attend mainstream schools full time and study alongside children with disabilities?

2. What specific steps is the government taking to ensure that inclusive education is available to all children, regardless of disability? Do these steps include:

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[12] Federal Law "On the Social Protection of the Disabled in the Russian Federation," No. 122-FZ, 2013, art. 15.

[13] Federal Law "On Education in the Russian Federation," 2013, art. 2, para 27.

[14] Federal Law "On Education in the Russian Federation," 2013, art. 5, para 5.1.

[15] Human Rights Watch telephone interview with Maria Perfilieva, November 12, 2013.

- Training teachers in the general school system to meet the learning needs of children with various disabilities?
- Specific infrastructural and informational accommodations in mainstream schools to make them accessible to all children, including children with disabilities?

3. How will the government take steps to inform parents and children of their right to inclusive education?

4. What is the plan and schedule for how the government will remove obstacles in children's communities to obtaining inclusive education, including by developing a plan to progressively equip school buses with wheelchair lifts and ensure that all children with disabilities live in accessible housing that enables them to safely enter and leave their homes?

Assistance and Support to Families with Children with Disabilities (Convention articles 2, 9, 18, 23, 28)

Children with disabilities and their parents are entitled to monthly government pensions, annual trips to resort towns, and healthcare under Russia's federal insurance system. Russia's policies on these forms of assistance assist the government in protecting children's right to benefit from social security (article 26). Children with disabilities and their parents whom Human Rights Watch interviewed valued these forms of assistance.

Russia must do more to comply with the Convention, however. Parents and disability rights activists repeatedly stressed the lack of government support services to enable children with disabilities to fully participate in their communities.[16] For example, as noted above, transportation to school is frequently not accessible. There is limited physical access to government-sponsored healthcare, rehabilitation services, and recreational activities for children with disabilities and their families, and children with various disabilities often face difficulties accessing these services and activities due to a lack of reasonable accommodations and discriminatory attitudes on the part of staff such as healthcare

[16] For example, Human Rights Watch interviews with Irina (pseudonym), Moscow, December 1, 2012; Inna (pseudonym), St. Petersburg, February 26, 2013; and Irina, Ulan-Ude, December 7, 2012.

personnel, for example.[17] In some cases when parents try to organize recreational activities, they face difficulties as well. For example, "Irina" (not her real name), the mother of a 10-year-old girl with a physical disability, struggled for over a year to obtain permission to bring her daughter to the swimming pool in her local government healthcare clinic, as medical staff feared that her daughter's appearance would scare other children.[18]

Without these provisions, raising a child with disabilities can become extremely difficult for families. Many mothers must remain at home with children full time to provide care. Government monetary assistance does not make up for the resulting lost income and for the lack of social services in children's communities. For example, Irina, mentioned above, left her job as an accountant in order to be able to attend school with her daughter. Her daughter's classes are held on the top floor of a public school and Irina must be present to carry her daughter safely up and down the stairs. Although Irina's husband has a full-time job, the family struggles to afford the mounting costs of her daughter's non-reimbursable healthcare expenses and the taxis that they must take because public transportation is inaccessible.[19]

The fact that the community-based services are inadequate and inaccessible can lead to parents making the wrenching decision to put their children in government institutions. This is contrary to the state obligation under the Convention to ensure that a child shall not be separated from his or her parents against their will, as well as the state's positive obligation to prevent children's separation from their parents on the basis of disability of either the child or one or both of the parents.[20] According to Russia's "National Strategy of Action for Children for 2012-2017," approximately 654,400 children have been given up from custody by their parents and reside in state custody.[21] The vast majority of these children reside in state institutions rather than with foster families. As of 2009 nearly 50 percent of children in residential care in Russia have disabilities, and nearly 30 percent of

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[17] Human Rights Watch interview with Tatiana (pseudonym), disability rights activist, St. Petersburg, February 25, 2013.

[18] Human Rights Watch interview with Irina (pseudonym), Moscow, December 1, 2012.

[19] Ibid.

[20] UNICEF, Committee on the Rights of the Child, "Separation from Parents," Implementation Handbook for the Convention on the Rights of the Child, 2007, http://www.unicef.org/publications/files/Implementation_Handbook_for_the_Convention_on_the_Rights_of_the_Child_Part_1_of_3.pdf, accessed November 8, 2013, p. 123.

[21] "On the National Strategy of Action for Children for 2012-2017 [О Национальной стратегии действий в интересах детей на 2012 - 2017 годы]," Decree No. 761 from 6.1.12, chapter 5, para. 2.

children with disabilities in Russia are in residential care. Given that children with disabilities constitute approximately 5 percent of Russia's total child population, children with disabilities are greatly overrepresented in state institutions.[22] According to a recent statement by Russian children's rights ombudsmen Pavel Astakhov, approximately 84 percent of children living in state institutions have at least one living parent.[23]

While the reasons children end up in institutions are complex, lack of government support is a significant factor. A survey by Partnership for Every Child (covering 161 parents of children with disabilities) found that an absence of medical, social, and psychological services that correspond to families' needs was an important factor impacting parents' decisions to relinquish custody of their children to the government.[24] For example, in 1996 "Karina" (not her real name) sent her then two year-old son to a state institution for children age four and below in the Leningrad region. Her son was born with a developmental disability and his pediatrician told Karina that the appropriate medications for his healthcare would be available only in institutions. Karina left her son in institutional care throughout his childhood because she reported that there were no community support services such as healthcare, inclusive schools, and recreational centers to help her care for him while she continued to hold a job in order to support her family.[25]

In its "National Strategy of Action for Children for 2012-2017," the Russian government names as two key problems affecting children the "widespread phenomenon of termination of parental rights and parental abandonment" and "inequality among subjects of the Russian Federation as regards the quantity and quality of available services for children and their families." The document recognizes the right of each child to live and be raised in a family and to maximize his or her potential. It names "vulnerable children,"

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[22] Joanna Rogers, "Briefing note – the evolution of state policy in the Russian Federation in relation to children with disabilities and their families," Partnership for Every Child – Russia, May 15, 2012.

[23] "Number of orphans down, more kids with parents still alive in orphanages in Russia – Russian children's rights ombudsman," *Russia Beyond the Headlines*, March 15, 2013, http://rbth.ru/news/2013/03/15/number_of_orphans_down_more_kids_with_parents_still_alive_in_orphanages_23901.html, accessed October 23, 2013.

[24] M.M. Emetz, I.M. Zinchenko, and K.A. Limanskaya, et. al, "Factors affecting placement of children with special needs in government care institutions [Факторов попадания детей с особыми потребностями в государственные воспитательные учреждения]," Partnership for Every Child-Russia, 2011, http://www.p4ec.ru/images/stories/p4ec/Materials/2.pdf, accessed October 23, 2013.

[25] Human Rights Watch interview with Karina (pseudonym), St. Petersburg, June 25, 2013.

including children with disabilities, as of particular concern. One key measure named in the strategy is the "provision of fully accessible services to families with children, including through the development of family support services," among other services such as crisis centers for mothers with children to prevent children from being institutionalized.[26] While Human Rights Watch recognizes the importance of this and other plans outlined in the strategy to support families of children with disabilities, we urge the Committee to seek more specific information on how these measures are being implemented and monitored throughout Russian cities.

Human Rights Watch hopes to see the Committee seek the following information during its upcoming review of Russia:

1. What steps is the government taking to make services such as accessible housing, transportation, inclusive education, healthcare, and recreation accessible to children with disabilities?

2. How will children with disabilities and their families be informed of their rights and entitlements to accessible social services in their communities?

3. How will the quality and accessibility of these services be monitored throughout Russian cities? What mechanisms are in place for children to participate in the monitoring and to make their views known?

Lesbian, Gay, Bisexual, and Transgender Children (Convention articles 2, 9, 13, 16)

Human Rights Watch has been monitoring the human rights situation for LGBT persons in Russia over the past 10 years and is concerned about legislation recently passed that violates the rights of LGBT children. In June the Russian parliament passed amendments to the Federal Law "On Protecting Children from Information Harmful to their Health and Development." The amendments ban disseminating among minors information promoting

[26] "On the National Strategy of Action for Children for 2012-2017 [О Национальной стратегии действий в интересах детей на 2012 - 2017 годы]," Decree No. 761 from 6.1.12, chapter 1, part 1, para. 4-5.

the "attractiveness of nontraditional sexual relationships," and providing a "distorted notion of social equivalence of traditional and nontraditional sexual relationships."

Dissemination of information about "nontraditional sexual relationships" is equated with dissemination of information about illicit drug use and suicide. It applies to press, television, radio, and the Internet (Federal Law 135-FZ).[27] The law does not define "nontraditional" but it is widely understood to mean lesbian, gay, and bisexual relationships. The law builds on similar regional bans that already existed in 11 other cities in Russia. Public debates before and after the law's adoption have included hateful, discriminatory, and degrading remarks about LGBT people in Russia, including on state television stations.

In 2002 the Committee criticized British legislation prohibiting teaching about homosexuality in schools, concluding that the state needed "to provide adequate information and support to homosexual and transsexual young people."[28] The Committee advised the United Kingdom to repeal the law that prohibited information about homosexuality to children. The law was subsequently repealed.

The Russian law has the potential to harm children by sending the message that it is wrong to be LGBT and removing sources of information and support. Even though the law's supporters have argued that the law is intended to protect children, it violates children's right to seek, receive, and impart information and ideas of all kinds to develop their identity and assess their health and sexuality. This includes information about homosexuality. This law and hateful remarks about LGBT people that public figures have made following its passage have influenced LGBT and other human rights organizations' decisions to limit their services to LGBT people over 18, in part for fear of violating the law.

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[27] "Amendments to Article 5 of the Federal Law 'On Protection of children from information harmful to their health and development' and some legislative acts of the Russian Federation in order to protect children from information that promotes the denial of traditional family values [О внесении изменений в статью 5 Федерального закона «О защите детей от информации, причиняющей вред их здоровью и развитию» и отдельные законодательные акты Российской Федерации в целях защиты детей от информации, пропагандирующей отрицание традиционных семейных ценностей]," Federal law No. 135-FZ, June 29, 2013.

[28] Committee on the Rights of the Child, "Concluding observations of the Committee on the Rights of the Child: United Kingdom of Great Britain and Northern Ireland," 2002, CRC/C/15/Add.188. Para 43 – 44.

Limited services have in turn left LGBT children without access to important sources of information and support significant to their health and protection of their rights.

In September Russian lawmakers introduced a bill to remove children from families if one or both parents is "of a nontraditional sexual orientation." That bill was temporarily withdrawn in October, but the bill's author, Russian State Duma Deputy Alexei Zhuravlev, from the ruling party "United Russia," has stated that he intends to reintroduce it after making certain changes. Should the law be passed, it would violate children's rights to be protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members; to not to be forcibly separated from their parents; and to freedom from arbitrary or unlawful interference with his or her privacy and family.
Human Rights Watch encourages the Committee to urge the Russian authorities to do the following:

1. Repeal Federal Law 135-FZ.

2. Issue a public statement from the highest level of government indicating gay, lesbian, and bisexual relationships and transgender identities are legitimate and deserving of respect.

3. Take legislative steps to ensure that children have access to information that enables them to develop their identity and assess their health and sexuality, including information on the rights and dignity of LGBT persons and on health for LGBT persons.

4. Publicly state that the government is opposed to any legislation denying parental rights to one or both parents of "nontraditional sexual orientation."