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Russia's Disabled "Orphans": Suggestions for Institutional Change

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I. Introduction

Disability is a pervasive stigma in many cultures worldwide, but in Russia that stigma manifests very early on.¹ For a child born with a developmental disability, the attitudes and fears from parents without a clear understanding of how to care for them can lead to their placement in state institutions for such children.² Those institutions, in turn, tend to treat these children as burdens, keeping them isolated and without resources that could help them develop the kinds of verbal skills and mobility that they will need to thrive as adults.³ As of 2014, there were an estimated 45,000 disabled Russian children living in state institutions.⁴

The situation for disabled children and for disabled people of any age in Russia is changing, with dramatic improvements since the 1990s.⁵ However, given the constitutional and legislative commitments that the nation has undertaken as well as the international agreements it has ratified, more remains to be done. In particular, legislative reform, increased funding, and above all greater involvement by NGOs would assist the system of institutionalization of disabled children in complying with the legal framework within which the Russian Federation exists.

II. Background on Institutionalization of Disabled Children in Russia

¹ See Liepa V. Boberiene & Ekaterina Yezykova, *Children with Disabilities in Russian Institutions: Can the West Help Protect the Most Vulnerable?*, 84 AM. ORTHOPSYCHIATRIC ASSOC. 3, 266, 267 (2014).

² *Id.*

³ See *Abandoned to the State: Cruelty and Neglect in Russian Orphanages*, Human Rights Watch (Dec. 1998), <https://www.hrw.org/sites/default/files/reports/russ98d.pdf>.

⁴ Boberiene, *supra* note 1 at 270.

⁵ Arianna Nowakoski, *Human Rights in Russia and the Former Soviet Republics*, TOPICAL RESEARCH DIGEST 1, 10, 14 (2007), <http://www.du.edu/korbel/hrhw/researchdigest/russia/russia.pdf>.

A. History and Cultural Background of Internats

Certain Russian “orphanages,” or internats (интернаты), host many children who are not orphans but rather are disabled in some way. In fact, a very large portion of the institutionalized children in Russia are not only severely impaired but also not orphans at all; 70% of the total institutionalized Russian children in 2012 were not orphans, and almost half had disabilities.⁶ This comes partly from a Soviet legacy of collectivizing childcare, which promoted a culture of parents distancing themselves from the childrearing process and rather entrusting their education and upbringing to the state—“all children are children of the state.”⁷ Children who were problematic or difficult to care could be rejected by their parents and put into state care at these “orphanages.”⁸ Stigma associated with disability has also been pervasive for decades, as exemplified by denial that such people even existed within the realm of the Soviet Union.⁹ When institutions were built to house the disabled, such institutions were built on the outskirts of cities, out of sight of the day-to-day lives of other citizens.¹⁰

The children in those institutions are still isolated from society in a way that harms them and perpetuates the stigma of disability that pervades the culture. Some are only allowed to see their parents if they are then isolated from the other children for a “quarantine” period, which deters parents from visiting, and many of these institutions

⁶ Ekaterina Evdokimova, *Institutionalization of Children with Impairments in the Russian Federation: The Solution That Never Was* 1-14 (April 10, 2014) (Erasmus University Rotterdam, unpublished article) (on file with the author).

⁷ Liya Kalinnikova & Sven Trygged, *A Retrospective on Care and Denial of Children with Disabilities in Russia*, 16 SCANDINAVIAN J. OF DISABILITY RESEARCH 229, 239 (2014).

⁸ Sarah D. Phillips, “There Are No Invalids in the USSR!”: *A Missing Soviet Chapter in the New Disability History*, 29 DISABILITY STUDIES QUARTERLY 3 (2009), [HTTP://WWW.DSQSDS.ORG/ARTICLE/VIEW/936/1111](http://www.dsqsds.org/article/view/936/1111).

⁹ *Id.*

¹⁰ Interview with Anna Klepikova, European University at St. Petersburg, St. Petersburg, Russia, March 20th, 2017; Kalinnikova, *supra* note 7 at 240.

are so underfunded or understaffed that the children receive very little human contact.¹¹ Large institutions in the major cities may hold 500-1,000 disabled children, with basically all of them being “closed” institutions where strangers may not visit or volunteer, and only select NGOs may send volunteers or employees.¹² In the worst of these situations, children have no communication, no education, and no recreation; they are left in bed all day, thirsty and hungry because the staff wants to minimize cleaning them, bathed once a week, and sometimes forcibly medicated or sedated as punishment for bad behavior.¹³ Even if the initial diagnosis that led to a child’s institutionalization was mild (such as cleft palate) or incorrect, it becomes self-fulfilling: deprivation from contact, activity, and stimulation leads to “profound socioemotional, cognitive, and behavioral difficulties” that perpetuate the necessity of their institutionalization.¹⁴

B. Parents Choosing Internats Over Home Care

Given the conditions in institutions, one might wonder what leads parents to place children in state care. Most often, this is because of a lack of resources. Many fathers leave their families when a child is born with a disability, either due to a belief that the disability could not have come from them and thus that their wife has been unfaithful, or due to a belief that they could not possibly have had genes that would produce a disabled child, and thus that their wife is “tainted.”¹⁵ Both of these reasons are of course grounded in misunderstandings about the nature of disabilities.

Even if a parent or parents decide to raise a child with disabilities, assistance from the state is mismatched for that choice. At most, parents get state assistance of about

¹¹ *Abandoned to the State*, *supra* note 1.

¹² Interview with Anna Klepikova, *supra* note 6.

¹³ *Id.*

¹⁴ Boberiene, *supra* note 1 at 267.

¹⁵ Interview with Anna Klepikova, *supra* note 6.

30,000 rubles per month (about \$500 USD) while raising a child with disabilities, and even then they must keep a record of how they spend that money.¹⁶ In contrast, in Moscow, institutions are given about 70,000 rubles per month (about \$1,200 USD) per child, although there are serious doubts about whether this money is reaching the children or whether there is corruption at play.¹⁷ Even a lack of information on the availability of these state resources (or charitable resources) can lead parents to give up children just from fear of the daunting task of finding ways to care for them.¹⁸ Recent rules have also limited the number of parents who even have access to state assistance, supposedly following Germany's model of providing payments based on severity of disability.¹⁹ Here, that means that children must have 60% or less of their bodily functioning to qualify for disability benefits.²⁰ All in all, this unnecessarily tips the scale for the uncertain parent more in the direction of institutionalization than for home care.

III. Relevant National and International Commitments

Russia ratified the U.N. Convention on the Rights of the Child (UNCRC) in 1990 and the U.N. Convention on the Rights of People with Disabilities (UNCRPD) in 2012.²¹ The UNCRC lays out state commitments to protecting the best interests of the child, protecting children's right to development, and respecting the rights of parents. The UNCRPD is a commitment to protecting the equal enjoyment of rights of disabled people

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ Clare Bigg, *Russia's New Disability Rules Prompt Outrage as 500,000 Lose Benefits*, THE GUARDIAN (Mar. 18, 2016), <https://www.theguardian.com/world/2016/mar/18/russia-disability-rules-outrage-lose-benefits>.

²⁰ *Id.*

²¹ Convention on the Rights of the Child, Nov. 20, 1989, 1577 U.N.T.S. 3; Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3.

to freedom and dignity. U.N. recommendations on how to incorporate the rights of disabled children into domestic policy focus on inclusion, rehabilitation, and equal access to public services.²² They go much farther than that the children must be kept alive, without education or rehabilitative services. Many internats operate on too little money and/or too few staff members, leading to problematic conditions for the children that could very easily be called not in their best interest as well as harmful to their development. Institutionalization itself has also been characterized as harmful on an international stage.²³ Furthermore, restriction of visitation and certain consequences from visitation (such as a quarantined period of isolation before children can return to the larger group after visits outside the institution, which deters parents from bringing them home for visits) appear clear violations of rights based on the UNCRC. In fact, some advocates go so far as to claim that Russia's current institutional conditions for disabled children violate 20 of the 41 articles of the UNCRC.²⁴

Domestically speaking, the Russian constitution has facially robust protections for disabled children. It promises state support for childhood and disability, social security for disability and “the bringing up of children,” care of children by their parents, compulsory basic education, and of course “equality of human and civil rights and freedoms.”²⁵ Domestic legal reform is also underway with regard to disability-based discrimination and access to education and public services for disabled children, and

²² UNICEF, *Promoting the Rights of Children with Disabilities*, Innocenti Digest No. 13 (2007), http://www.un.org/esa/socdev/nyin/documents/children_disability_rights.pdf.

²³ See Naomi Larsen, *Out of Sight: The Orphanages Where Disabled Children are Abandoned*, THE GUARDIAN (Sept. 26, 2016) (references to international movements for “deinstitutionalisation”).

²⁴ Boberiene, *supra* note 1 at 267–68.

²⁵ Constitution of the Russian Federation, 1993 rev. 2014, Art.s 7, 39, 38, 43, 19. https://www.constituteproject.org/constitution/Russia_2014?lang=en.

numerous federal laws attempt to address the needs of disabled citizens of all ages.²⁶ The federal government has also pursued programs oriented towards improving the lives of disabled children specifically, such as the 1998 Disabled Children program, the 2003 Children-Orphans Program, and the 2006 Social Support for the Disabled program.²⁷ However, advocates indicate that these laws and programs have been “largely symbolic and ineffective,” producing “virtually no impact.”²⁸

IV. Existing Efforts for Reform

A. Domestic Legislation

There is evidence that Russia is already working towards compliance with international law, as well as with its own constitution. Putin has called for decreases to the institutionalized population, and significant state funds go to the institutions each year, but the quality of life for the children has remained largely the same.²⁹ Also, as indicated above, a series of federal laws and federal programs have been undertaken as attempts to correct these problems, although they appear ineffective so far.³⁰

Recently, a law was passed that terminated parental rights if parents did not visit their institutionalized children at least twice a year.³¹ Now basically all parents do visit at

²⁶ See *Russia: Pass Laws to Protect Disability Rights*, Human Rights Watch (May 11, 2014), <https://www.hrw.org/news/2014/05/11/russia-pass-laws-protect-disability-rights>; Boberiene, *supra* note 1 at 267 (listing the Federal Law on Social Protection of People with Disabilities in the Russian Federation (1995), the Federal Law on State Social Protection (1999), the Federal Law on the Order of Distribution of Social Protection (2005), and numerous federal directives).

²⁷ Boberiene, *supra* note 1 at 267.

²⁸ *Id.*

²⁹ *Russia: Children with Disabilities Face Violence, Neglect*, Human Rights Watch, (Sept. 15, 2014), <https://www.hrw.org/news/2014/09/15/russia-children-disabilities-face-violence-neglect>.

³⁰ Boberiene, *supra* note 1 at 267–68.

³¹ Interview with Anna Klepikova, *supra* note 6.

least that often.³² Parents are also choosing to keep their disabled children at home more often than not, although this may be somewhat skewed by high rates of abortion for babies with high probabilities of being born disabled.

B. Adoption Policies

Some countries turn to international adoption to ease the burden on the state of caring for disabled children, but this is very rare in the Russian Federation. No same-sex couples and no single parents living a country that allows gay marriage are allowed to adopt Russian children, and since 2012, no United States citizen has been allowed to adopt Russian children.³³ The ban on American adoptions of Russian children was based on anecdotal, widely publicized examples of abuse and neglect of Russian children by American parents.³⁴ However, these adoption bans are tragic for disabled “orphans” in Russia—since the 1990s, foreign nationals have been adopting about 500 disabled children from Russian state institutions, with the majority of those adoptions being by American parents.³⁵ Russian lawmakers even attempted to propose an exemption to the ban for the 45,000 disabled children living in Russian institutions, but parliament refused to discuss it.³⁶

The pivot away from foreign adoption was followed by a spike in domestic adoptions as citizens felt it their duty to care for parentless children, but the rates of

³² *Id.* While it seems dissonant for parents to shut their children into state institutions and then also feel strongly about keeping their parental rights, it may be that such parents truly feel that institutionalization is the best and happiest life for their children.

³³ Interview with Anna Klepikova, *supra* note 6; Boberiene, *supra* note 1 at 269–70.

³⁴ Boberiene, *supra* note 1 at 270 (noting that in 22 years and more than 60,000 adoptions of Russian children by American families, there have been 19 deaths, compared to 1,500 deaths of Russian children in Russian adoptive families).

³⁵ *Id.* at 269.

³⁶ *Id.* at 270.

adoption for disabled “orphans” still remain low.³⁷ Even of those adopted, there is a problematic trend of people in the rural countryside adopting children for free labor, so it does not appear to be the best avenue for improvement.³⁸

C. Russian NGO Efforts

Russian NGOs do significant work to improve conditions in internats and to affect the public stigma surrounding disabilities such that parents may feel more willing and capable of taking care of children with disabilities. Perspektiva is a particularly influential group in this respect, putting together volunteer coordination, activities for children, public campaigns for disability acceptance such as film festivals, and resources for parents. They are also the only group allowed at certain internats in St. Petersburg and perhaps elsewhere.³⁹ This gives them the opportunity to provide both services to the children and insight for the public into current conditions. The Soldier’s Mothers Committee (Союз Комитетов Солдатских Матерей России) and others like it tend to indicate that where dedicated, grassroots, domestic NGOs get involved, they meet with more success than foreign NGOs and other international actors.⁴⁰

D. International Efforts

In the past, the United States Agency for International Development (USAID) and the United Nations Children’s Fund (UNICEF) have both devoted significant resources to

³⁷ Dmitri Sudakov, *Russia May Let U.S. Parents Adopt Russian Orphans Again*, PRAVDA REPORT (Jan. 11, 2017) (claiming that 1,666 disabled children were adopted by Russians in 2016). It is difficult to get accurate figures on this, especially since thousands of adopted children are returned to orphanages within a year. See Alexandra Tyan, *The Russian Parents Challenging Stigma Surrounding Adoption*, THE GUARDIAN (Aug. 31, 2015). Even if that figure is accurate, it amounts to roughly 4% of the institutionalized children with disabilities in Russia getting adopted each year. See Boberiene, *supra* note 1 at 270.

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ *Id.*

improving the lives of Russia's disabled children, partnering with Russian NGOs and Russian local governments to institute more educational and rehabilitative services for disabled children.⁴¹ Western NGOs like EveryChild, Action for Russia's Children, and CoMission tended to be oriented towards helping families raise their disabled children.⁴² Rather than focusing on improving conditions in the institutions, where foreigners were typically not allowed to volunteer or even be on the premises, these NGOs provided financial support, tutoring, free legal advice, training seminars, counseling seminars, summer camps, and other resources to biological and foster families who might otherwise struggle to care for their disabled children.⁴³

In the wake of the 2012 foreign agent law, virtually all international aid organizations in Russia shut down, either because of formal expulsion by the government (USAID) or because of raids, halt orders, lawsuits, and loss of credibility following their registration as "foreign agents."⁴⁴ For these reasons and others, that law has drawn international criticism.⁴⁵

V. Suggestions for Best Practices

A. Regulatory Legislation

The Russian government could establish minimum conditions that are acceptable for internats, below which they will not receive funding. This could include things like

⁴¹ Boberiene, *supra* note 1 at 268.

⁴² *Id.*

⁴³ *Id.*

⁴⁴ *Id.* at 269. For a more detailed analysis of this law, its context, and its implications, see Françoise Daucé, *The Duality of Coercion in Russia: Cracking Down on "Foreign Agents,"* 23 DEMOKRATIZATSIYA: THE J. OF POST-SOVIET DEMOCRATIZATION 57 (2015).

⁴⁵ See, e.g., HUMAN RIGHTS WATCH, *Russia: Government v. Rights Groups* (June 1, 2017); *European Court of Human Rights Begins Investigating Russia's "Foreign Agent" Law,* THE MOSCOW TIMES (Mar. 29, 2017).

that the children be allowed a certain amount of movement and communication every day or that they should be given water when they request it. Alternatively, as increased parental visitation might also increase public awareness of the conditions in these institutions, the existing requirement that parents visit their children twice a year in order to maintain parental rights could be gradually increased over time, such that more and more parents will be coming in and out of internats at different times of year. This could help drive public support for increased funding or stricter rules in internats and might also push parents to choose to keep their children at home, which could be both better for the child who goes home and better for the institution that can then devote its limited resources to fewer children.

Legislation also need not be directed at institutions directly; the more daycares that welcome disabled children and the more schools provide specialized education for them, the more people will be willing to keep their children at home rather than in state institutions. Advances in equal access to education and public facilities could also have the secondary effect of combating the existing social stigma of people with disabilities, which could get at the heart of the problem in the first place. Whereas it is not uncommon for schoolkids to taunt each other by calling one another “Down’s Syndrome,”⁴⁶ that kind of inculcated prejudice from a young age could be counteracted by exposure to real human people who interact with those kids at school. The more normal such people seem to the general public, the less resistance there will likely be to legislation in the direction of equality for them, and the less likelihood that disabled children will be tucked out of

⁴⁶ *Id.*

sight in institutions that focus more on keeping them alive than on preparing them to be involved participants in society.⁴⁷

B. Increased Funding

Assuming that government funding actually reaches the children who are cared for in these institutions, an increase in funding could greatly improve conditions, as more staff and doctors make for better attention and happier patients. It could also allow for hiring of support staff who are dedicated primarily to interacting with the children, helping them develop verbal skills, and teaching them skills they will be able to use as adults, since the situation for disabled adults is not better and if anything may be much worse than it is for children. As it stands, work is hard to come by for disabled adults, and there are basically no dedicated assisted living institutions for disabled adults, with the exception of a pilot program in St. Petersburg modeled on Swedish assisted living facilities.⁴⁸

Alternatively, the state could increase funding that is directed at families to assist them in caring for children with disabilities. This could increase the number of parents who choose to keep children at home, as they find it more feasible to hire nannies, invest in specialized equipment, pay for medical care, and take other measures that they would not have in the absence of significant state assistance. This could also increase the number of parents who keep children at home, in that they can see the relative amount of assistance their children would receive at an institution (which currently tend to receive more money per child per month than folks at home do) and come to the conclusion that the child would not be “better off” in such an institution.

⁴⁷ *Id.*

⁴⁸ *Id.*

C. NGO Involvement

The bottom line is that the more NGOs can be involved in Russian institutions for disabled children, the better. They can provide material and staff support, they can help with community integration and lobbying efforts on behalf of the children and their parents, and they provide a much-needed source of oversight for how government funds are spent within state institutions.

However, the network of NGOs that advocate for children with disabilities in Russia has experienced much slower development than it could, in part because of the “foreign agent law.” Passed in 2012, that law labeled any NGO a “foreign agent” if it accepted payment from foreigners or foreign governments and engaged in “political activity” (such as lobbying the Duma for increased protection of children with disabilities). Once labeled a foreign agent, NGOs face intrusive audits, a requirement that they note on all official publications that it’s coming from a “foreign agent,” and often harassment.⁴⁹ These burdens can be fatal to NGOs: at least 20 of the 70 NGOs that had been listed as foreign agents in June 2015 had ceased activity.⁵⁰

To be fair, the foreign agent law has not been uncontested, even on the national level. In 2014, the Russian Human Rights Commissioner brought a challenge to the law

⁴⁹ Kate Lyons & Mark Rice-Oxley, *Harassed and Shunned, the Russians Labelled Foreign Agents by the Kremlin*, THE GUARDIAN (Apr. 26, 2015), <https://www.theguardian.com/world/2015/apr/26/harassed-and-shunned-the-russians-labelled-foreign-agents-by-kremlin>.

⁵⁰ Council of Europe Commissioner for Human Rights, *Call to Bring Russian NGO Legislation in Line with European Standards* (July 9, 2015), <http://www.coe.int/en/web/commissioner/-/council-of-europe-commissioner-for-human-rights-reiterates-his-call-to-bring-russian-ngo-legislation-in-line-with-european-standards>.

in the constitutional court, which failed.⁵¹ Human rights groups, political activists, and interested parties have been protesting it, as in the PEN Center's open letter, but as yet these efforts have fallen short.⁵² International opposition to the foreign agent law has as yet been similarly ineffective.

Without a shift toward allowing foreign NGOs to participate or at least to allow domestic NGOs to conduct ordinary business, which might include the occasional contact with foreigners, many of these efforts to reform are dead in the water. Given that NGOs appear to be the most effective route to improve the quality of life for institutionalized Russian children, it is imperative that the Russian government alter legislation that hinders those efforts.

D. Other Considerations

Still, much as disability rights advocates may wish to bring about swift and bold changes to institutions and legal structures in Russia, it is worth keeping in mind that any kind of cultural reform in public attitudes toward disability there is nascent. From a United States perspective, we have the benefit of decades of very uncomfortable transitions in terms of both quality of care and stigma of the disabled—since the 1960s, our understandings of disabilities and mental illness have changed significantly, and we

⁵¹ Oleg Sukhov, *Human Rights Groups to Close Over "Foreign Agent" Label*, THE MOSCOW TIMES (Apr. 9, 2014), <https://themoscowtimes.com/news/human-rights-group-to-close-over-foreign-agent-label-33809>.

⁵² PEN Center, *Russia: Writers and Academics Speak Out Against Law on Foreign Agents* (Feb. 5, 2016), <https://pen.org/russia-writers-and-academics-speak-out-against-law-on-foreign-agents/>.

are still trying to find models of care that work. That process has been a slow and dark chapter in our own history.⁵³

Comparatively, Russia only began its mental illness and disability reforms in the 1990s. As such, the relevant parallel to United States conditions should probably be what institutions looked like in the 1980s, about twenty years into reform, rather than expecting Russian attitudes and infrastructure to match Western standards immediately. This is by no means a reason for reform to stop or slow (it is absolutely critical that progress continue to be made), but certainly it is worth considering, especially given that progress on this front is *not* stagnant.

While the domestic conditions that hamper improvement in equality for disabled children (such as the foreign agent law) should certainly be targeted with international disapproval, I have intentionally refrained from suggesting that trade sanctions or other kinds of international punishment would be helpful in pursuit of changing conditions for institutionalized children. Cultural attitudes, institutional limitations, and even legal structures change slowly. Advocates (Russian advocates, Russian NGOs, international NGOs with operations in Russia and direct contact with children) who are much closer to the ground than I (an able-bodied American law student) indicate that what these children need is increased acceptance from their parents and increased support from NGOs and the government. These things are not necessarily improved by blind rage and flat horror at the existing conditions that institutionalized children face. To the extent that international audiences could raise domestic awareness of the problem, such reports do

⁵³ See Burton Blatt, *Christmas in Purgatory* (1966); Deanna Pan, *Deinstitutionalization and its Consequences*, Mother Jones (Apr. 29, 2013), <http://www.motherjones.com/politics/2013/04/timeline-mental-health-america>.

serve a purpose, but they should be grounded in support for what will help rather than in pure opposition to what seems to be working too slowly.

VI. Conclusion

The conditions that institutionalized children with disabilities face in Russia are in conflict with Russia's international agreements and with their domestic commitments. The two main solutions, which work hand-in-hand, are to push more parents to raise disabled children at home and to improve the quality of care in state institutions. Both of these goals can be achieved through domestic legislation, increases in funding to parents of disabled children and to institutions that care for disabled children, and particularly through increased involvement of NGOs in volunteering, lobbying, and otherwise providing support for families and institutions that need it. Increased NGO involvement can only really follow if significant legislative changes take place.⁵⁴ While there is reason to believe that the trend of improvement in the lives of disabled Russians will continue over time, but there is no reason not to support efforts that will speed up such improvement.

⁵⁴ Chip Pitts, *Russia's New Treason Statute, anti-NGO and Other Repressive Laws: "Sovereign Democracy" or Renewed Autocracy?*, 37 HOUSTON J. INT'L LAW 114 (2015); Amnesty International, *Russia: Four Years of Putin's "Foreign Agents" Law to Shackle and Silence NGOs*, Nov. 18, 2016, available at <https://www.amnesty.org/en/latest/news/2016/11/russia-four-years-of-putins-foreign-agents-law-to-shackle-and-silence-ngos/>