Ensuring Access to Inclusive Education for Children with Disabilities:
Deinstitutionalization and Desegregation

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I. Introduction

International law guarantees all children the right to education without discrimination, and yet, millions of children are denied this right. Disabled children are less likely to attend school than others and children with intellectual or psychosocial (mental health) disabilities face disproportionate barriers to accessing education.1 This paper discusses two major barriers disabled children face in accessing the education that they are entitled to; institutionalization and segregation. The Conventions on the Rights of the Child (“CRC”) and on the Rights of Persons with Disabilities (“CRPD”) requires that children with disabilities be included in society equally with others.2 Inclusion must begin with equal access to education, given that education is recognized as both a right itself and a means to realize other fundamental human rights. When disabled children are denied education designed to meet their needs, their ability to maintain employment or other roles in society is diminished. Therefore, deinstitutionalization, desegregation and developing schools to be more responsive to diverse needs are effective means towards a more inclusive and equitable society.

Today, 8-10 million disabled children are confined in institutions worldwide.3 Many states have justified these practices as a means to provide specialized care or support “in the best interest of the child.”4 In many parts of the world, institutionalization is on the rise where children with disabilities have become commodities for orphanages that profit off “voluntourism”—the recent trend of well-intentioned foreigners paying thousands of dollars for

4 See CRC supra note 2, art. 3.
brief periods of work, despite lacking skills and training. Institutions are not in a child’s best interest and countless reports reveal that institutionalization and segregation exposes children to an increased risk of abuse and lifelong societal exclusion.

Aside from upholding human rights, there are economic arguments that make deinstitutionalization and desegregation attractive to states. Investing in educating disabled children increases employment and reduces welfare and future dependency costs. Research shows that investing in well-planned community-based services that provide meaningful learning opportunities for all children in mainstream schools is more cost-effective in the long run than funding large-scale institutions.

The Human Rights Council’s Resolution 37/20 called for “[e]mpowering children with disabilities for the enjoyment of their human rights, including through inclusive education.” In light of this, Human Rights Advocates calls attention to the widespread use of institutionalization of children with disabilities and/or segregated schooling systems. These practices are not only inconsistent with the CRC’s general principles and violate children’s right to inclusive education, but ultimately deprive them of the opportunities needed to lead a dignified life and contribute to the social, cultural, and economic vitality of their communities.

II. The Right to Inclusive Education

The right to quality education is a fundamental human right because it underpins individuals’ ability to enjoy all other human rights, specifically, “[e]ducation is considered to be both an end in itself, that is, a process through which personal development and respect are

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obtained and a means to an end, that is, an integral part of the achievement of social citizenship.”

The Salamanca Statement, produced at the 1994 UNESCO World Conference on Special Needs Education, provided that “[children] with special educational needs must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting these needs’ and that this approach “[is] the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all.” In 1997, the CRC Committee noted that legislation that segregates disabled children into separate institutions “for care, treatment or education” was “not compatible with the principles and provisions of the Convention.” Further, the Committee asserted in a 2001 General Comment on the aims of education that denying disabled children mainstream education alongside their non-disabled peers falls short of human rights standards.

Children with disabilities are entitled to quality inclusive education under the CRC and the CRPD. The CRC sets forth the legal basis for education in two articles—Article 28 addresses access to education guaranteeing an equal opportunity to all children, while Article 29 addresses quality of education directing schools to focus “[t]he development of the child’s personality, talents and mental and physical abilities to their fullest potential . . . [and] [t]he preparation of the child for responsible life in a free society.” Inclusive education is recognized under Article 24 of the CRPD, which requires that “children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability” and

12 See CRC, supra note 3, Articles 28, 29.
obligates states to “ensure an inclusive education system at all levels and lifelong learning.”13

While the right to education is universally recognized under international law, challenges in implementation persist. The CRC Committee identified four general principles necessary for the implementation of all other CRC rights: (1) non-discrimination (Art. 2); (2) the best interests of the child (Art. 3); (3) the right to life, survival and development (Art. 6); and (4) respect for the views of the child (art. 12).14 Each state party is obligated to ensure that these four principles are promoted through all measures taken towards fulfilling the right to education.

States fail to promote these principles when institutionalization or segregation are used as means to fulfill the rights of disabled children. First, institutions and segregated schooling are incompatible with the principle of non-discrimination because these measures deny children access to basic services and the enjoyment of rights because of their disability. Second, institutions can never be in the child’s best interest where, as reported by the UN Special Rapporteur on Torture, institutions have been found to subject children to violence, abuse, and an increased risk of torture.15 Third, segregating disabled children in separate institutions for care or education does not ensure an equal right to life, survival and development because the effects of such lead to “poor physical health, severe developmental delays, disability, and potentially irreversible psychological damage.”16 Lastly, the child’s views are not promoted through institutionalization or segregation because they fail to consider the child’s evolving capacities to participate in decision-making. States’ continued use of institutions or segregated schools for care or education of disabled children cannot be excused based on limited resources because states must make specific budgetary allocations for realizing disabled children’s rights, and these

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13 See CRPD, supra note 3, Article 24.
15 HRC, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, UN Doc. A/HRC/28/68, para. 33 (March 5, 2015).
allocations must be protected and prioritized in times of economic crisis.\textsuperscript{17}

III. Institutionalization and Segregation as Barriers to Inclusive Education

While many countries have phased out the use of institutions as solutions for care or education for disabled children, the practice is maintained and on the rise in others. Even where disabled children are not confined to institutions, they face barriers in accessing education because mainstream schools are unable to or refuse to accommodate their needs. As a result, disabled children are segregated in special schools or in their homes and are deprived of the learning experiences necessary to reach their full potential. The following are examples of countries that have been found to institutionalize, segregate, or exclude disabled children.

A. Russia

The Russian government has made positive legislative efforts towards implementing the right to inclusive education for disabled children, such as legislation prohibiting disability-based discrimination and increasing the number of students with disabilities in inclusive education.\textsuperscript{18} However, Russia’s practice of segregating disabled children in state institutions or specialized schools continues to thwart access to inclusive education and undermines the purpose of an education; promoting social integration and maximizing individual development.\textsuperscript{19}

The Russian government’s failure to ensure disabled children’s families have meaningful care alternatives or access to community-based services to support these children’s needs has resulted in institutionalization as the rule rather than the exception. In a 2012 survey of 10 countries, Russia had the highest rate of institutionalization; despite it having the lowest poverty

\begin{itemize}
  \item \textsuperscript{17} See CRC Committee, General Comment No. 19 on \textit{Public Budgeting for the Realization of Children’s Rights} CRC/C/GC/19 (2016).
  \item \textsuperscript{19} See CRC, \textit{supra} note 3, at Article 23(3).
\end{itemize}
rate. As of 2014, approximately 30 percent of disabled Russian children live in state orphanages, despite 95 percent of them having at least one living parent. Reports reveal that doctors and nurses advise parents to give up their disabled newborns because “children will be unable to develop and form relationships, [parents will be unable to care for them, or] children will die.” Parents also relinquish custody at older ages because of obstacles in accessing appropriate education and other social services for their children. Human Rights Watch reported that children are institutionalized because parents are uninformed about their children’s rights, their developmental capacities, or the social services available to support their child’s needs.

Many parents do not have a choice to raise a child with disabilities because government assistance is insufficient for their child-rearing needs. For example, parents reportedly receive about 500 USD per month while institutions in Moscow receive about 1,200 USD per month per child.

Children with certain types of learning disabilities, primarily intellectual and psychosocial, are denied education solely because of their disability. While the designation “uneducable” was outlawed in 2013, children with intellectual and psychosocial disabilities are isolated in separate wards or “lying-down rooms”, deprived of education and social interaction, and often subjected to psychological and physical abuse, resulting in severe psychological harm.

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22 Id.
23 Id. at 9.
and developmental delays. Consequently, these children are transferred without consent to adult mental institutions upon turning 18, where education and inclusion into society is unlikely. While Russian law requires consent prior to transferring a disabled person into an adult institution, several cases of young persons moved to an adult institution without consent were reported in late 2017.

Even though Russian law allows parents to choose between mainstream schools, special needs schools, or home schooling, mainstream schools either do not accommodate children well or they are too far away. As a result, children are de facto segregated because parents are forced to send them to boarding schools or institutions to ensure they can receive an education, albeit a limited one.

B. Lebanon

In 2017, the CRC Committee reported concerns on the high rate of children with disabilities living in institutions in Lebanon. Although Lebanon enacted a law in 2000 that ensured access to education for disabled children, there have been limited efforts towards implementation. Education for children with disabilities is not comparable due to lack of support or discriminatory admissions. The few eligible children who have access to education are still segregated in inadequate schools. Parents are more likely to place disabled children in a residential institution isolated from society and deprived of quality education because the state

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26 Id., at 5, 33.
does not provide educational support in mainstream schools and private schools are too costly.31

Lebanon hosts one of the largest populations of refugees per capita,32 yet access to education remains a challenge for disabled children, especially those with intellectual and psychosocial disabilities, particularly anxiety, post-traumatic stress disorder, and depression. Syrian refugee children with disabilities in Lebanon are twice as likely to have never gone to school compared to nondisabled Syrian refugee children.33 Disabled children are often denied admission to public schools because it “is considered a charity rather than a basic right for all.”34 For example, a Syrian mother could not enroll her two children with intellectual disabilities in public school because it did not “accept these types of cases . . .” and “other students would make fun of [them].”35 Even when admission is granted, schools are unlikely to accommodate the needs of children with intellectual or psychosocial disabilities. It was reported that a school refused to accommodate a Syrian refugee child with Hunter Syndrome, a developmental disability, by not allowing him to sit in the front row to help him concentrate.36 In both cases, the children were forced to remain home and completely excluded from accessing any education.

C. Guatemala

In 2016, the CRPD Committee urged Guatemala to stop institutionalizing children after reviewing reports of pervasive abuse.37 In 2017, 41 children were killed in a suspicious fire after

36 Id.
they protested their forced prostitution in a state institution.\textsuperscript{38} A year later, survivors were found in abusive institutions, and many are believed to have been trafficked.\textsuperscript{39}

An overwhelming number of disabled children live in orphanages, despite 90–95 percent having living parents.\textsuperscript{40} Disabled children are unable to exercise their right to inclusive services, such as education, due to lack of available local support. Guatemala spends 45 times as much per child, to institutionalize them than it does to support the families of disabled children at home.\textsuperscript{41} Of the limited national laws and policies relevant to disabled children, none assign funds or specify special programs or implementation strategies.\textsuperscript{42}

In 2016, the CRPD Committee expressed concern over Guatemala’s failure to ensure that international funding was used in accordance with disabled children’s rights. Limited funding derived from the growing trend of voluntourism in Guatemala has encouraged and increased institutionalization. From 2013 to 2017, private orphanages supported by churches, volunteers, private charities and international donors increased from 134 to 163.\textsuperscript{43} Many institutions receive “up to $10 million USD per year, from fees that they charge volunteers,” which incentivizes child trafficking to expand operations.\textsuperscript{44} The US State Department reported that “[t]hese orphanages facilitate child trafficking rings by using false promises to recruit children and exploit them to profit from donations.”\textsuperscript{45}

IV. Dismantling Barriers:

\textsuperscript{38} Id. at 4.
\textsuperscript{39} Id. at 4–6.
\textsuperscript{40} Id.
\textsuperscript{41} Id. at 25.
\textsuperscript{43} DRI, Submission to the Committee on the Rights of the Child: Situation of Institutionalized Children in Guatemala, https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/GTM/CRC%20NGO%20GTM%2027109%20E.pdf.
\textsuperscript{44} DRI, supra note 37 at 19.
The barriers disabled children face in exercising their rights are not because of their disabilities itself; barriers are generated through systems that treat them as objects of care and protection, which perpetuate marginalization and exclude them from meaningful participation in society. Therefore, governments must invest their resources in ways that will remove barriers and support the individual development of each disabled child. There is no blueprint for countries to transition from a system of institutionalization and segregation toward an inclusive system. Each state must develop comprehensive national strategies for deinstitutionalization tailored to its specific circumstances and that conform with the principles and guidelines of the CRC and CRPD. While the process of developing services that support inclusion and participation in communities is gradual, states must take certain immediate measures towards deinstitutionalization and desegregation.

A. Policies and Programs to Prevent Child Abandonment

In countries where institutions are the predominant form of care, many parents are pressured by medical staff to relinquish custody of disabled children to the state after birth. Investment in early intervention programs has been successful in preventing families from abandoning disabled children, especially those with intellectual impairments. Rather than persuading parents to institutionalize their child for care, medical personnel refer parents to these programs. These programs integrate health and social services as well as provide an individualized approach and mobile services for each family to aid and stimulate the child’s early development. Seven countries with high institutionalization rates—Armenia, Bulgaria, Croatia, Greece, Ireland, Moldova, and Slovakia—have found success with intervention centers in recent years in both preventing institutionalization and segregation. 46

Bulgaria had over 35,000 children placed in institutions in 2000 and significantly reduced
the number to 3,592 in 2013.47 In partnership with NGOs and the European Union and
Commission, the government has effectively invested funds to support the transition from
institutions to community-based services in several areas.48 Bulgaria enacted the Pre-School and
School Education Act, which established the right of disabled children to specialized support,
including resource teachers within mainstream schools. As of 2015, the number of newly
enrolled disabled children in kindergartens and preschool more than tripled the target number set
by Bulgaria’s “Social Inclusion Project.”49 While Bulgaria still has a long way to go with
implementation, the government’s efforts towards inclusion are promising.

B. Moratorium on New Admissions and Expand Alternative Care Options

The UN Guidelines for Alternative Care call on states to establish a moratorium on new
admissions of children under three years-old to institutions because these are the most
impressionable years in a child’s life, especially children with intellectual and mental health
disabilities.50 The primary reasons children end up in institutions is because of a lack of
accessible alternative support and the existence of institutions. Therefore, moratoriums should be
accompanied by plans to increase financial and human support for existing family or
community-based care options, such as adoption or foster systems.

In 2013 to 2014, nearly 34,000 children were confined to institutions in Japan, 3,000 of
which were infants.51 Many parents choose institutions rather than foster care or adoption
because these systems lack support and monitoring. There is also an incentive for medical staff

47 UNICEF, *Compendium of Promising Practices to Ensure that Children Under the Age of Three Grow Up in a
48 Id.
49 World Bank Group, *Bulgaria Social Inclusion Project*, 13 (26 June 2018),
to suggest institutions because they operate with government subsidies based on the number of children. However, legislative reform has made progress towards deinstitutionalization. In 2016, Japan’s Minister of Health, Labour and Welfare amended its 72-year-old Child Welfare Act to recognize a child’s right to grow up in a family setting. In 2017, Japan’s Health Ministry adopted the “New Vision for Alternative Care,” which outlines goals towards deinstitutionalization, including a moratorium on placing children younger than pre-school age in institutions. While these amendments are a step in the right direction, there have been limited measures towards implementation.

Italy was the first state to initiate and succeed at deinstitutionalization because of radical legislative and social reforms. While Italy’s efforts began over three decades ago, preliminary measures profoundly influenced its success. Italian Law 180 or the Mental Health Act of 1978 prompted the gradual close of public institutions through the immediate end to new admissions, development of community-based services, such as residential care communities or family support services, and relocation of medical staff from closed institutions to these services. Italy is also a leader in ensuring disabled children are included in mainstream education systems. Disabled children are legally guaranteed to attend mainstream schools and receive tailored educational support. Today, 98 percent of disabled children attend such schooling, which makes Italy the only EU country where nearly all disabled children are educated in the general

52 Id. at 56.
education system.\textsuperscript{56}

\textbf{C. Regulate International Aid and Resources}

In recent years, connections between orphanage voluntourism, increased institutionalization, and orphanage trafficking have been reported in many developing countries, such as Liberia, Uganda, Ghana, Nepal, Guatemala, Haiti, Cambodia, Indonesia, Botswana, and South Africa.\textsuperscript{57} Voluntourism has become an estimated 2.6 billion-dollar industry per year, with 1.6 million people travelling from wealthy nations to developing nations for short-term, unskilled volunteering in orphanages each year. The impact has not only increased institutionalization in these countries, but has undermined reform efforts towards inclusion. To keep up with the demand, orphanages target impoverished parents of disabled children and convince them that their child will receive care and education. Many religious organizations establish orphanages in response to crises and keep children there long after the crisis is over because the donations keep arriving. While volunteers may have good intentions, they inadvertently cause harm to children by maintaining and expanding reliance on institutions. Under the CRC and CRPD, both receiving and sending governments must ensure resources are being used to meet their obligations. Sending governments need to tackle the demand for orphan tourism fostered by their education, charity, tourism, and faith-based sectors. Receiving countries must ensure resources go towards fulfilling the rights of disabled children.

The Australian government is the first country to introduce measures to redirect their volunteers and funding to keep children out of institutions and segregated settings. The Department of Foreign Affairs and Trade launched a campaign to “prevent Australians from

\textsuperscript{56} Inclusion Europe, \textit{Rights of Children with Disabilities in the International Human Rights Framework and European Union Polcie: Norms, Concerns and Opportunities,} 17 (June 2014), \texttt{http://www.inclusion-europe.org/childrights4all/images/HoV_Policy_briefing_final.pdf}.

inadvertently contributing to child exploitation through the practice of orphanage tourism, including by participating in misleading volunteer programs.”⁵⁸ Additionally, Australia introduced the Modern Slavery Bill, which will require companies who meet the monetary reporting threshold to report how they identify, investigate and mitigate any risks associated with trafficking and slavery, including orphanage trafficking.⁵⁹ While much more remains to be done, governments should be urged to define, prevent and punish contributory acts of institutionalization at home and abroad.

V. **Recommendations**

Human Rights Advocates (“HRA”) urges the Council to:

1. Reaffirm the need for states to deinstitutionalize and desegregate children with disabilities from special needs schools and invest resources to develop an inclusive education system with deadlines and evaluation measures.

HRA urges states to:

1. Prioritize the deinstitutionalization of children with disabilities by placing a moratorium on new admissions and ensuring resources are directed towards developing community-based alternatives to institutions;

2. Ensure funds and international development aid are not being used to perpetuate the institutionalization or segregation of children with disabilities by not supporting the transition to community-based services, including individualized support in mainstream schools;

3. Amend laws and policies to recognize and support all children with disabilities, including non-physical conditions and refugees.

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