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# The Right of All Children to Grow Up with a Family under International Law: Implications for Placement in Orphanages, Residential Care, and Group Homes

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## ABSTRACT

This article describes the right of all children to live and grow up in a family as it has evolved thirty years after the adoption of the U.N. Convention on the Rights of the Child (CRC) and since the 2006 adoption of the U.N. Convention on the Rights of Persons with Disabilities (CRPD). The article examines the implications of this right for the millions of children placed in orphanages, residential care, and group

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# homes around the world.

The CRC favors the placement of children with a family, but it does allow for the placement of children in "suitable institutions" when families are unavailable. In General Comment No. 9, the U.N. Committee on the Rights of the Child states that institutions should be "transformed" into smaller residential facilities and used only as a "last resort." The United Nations Guidelines on Alternative Care calls for the elimination of large institutions but also allows for longterm placement in smaller residential homes. The more recently adopted U.N. Convention on the Rights of Persons with Disabilities (CRPD) now creates stronger protections through a combination of Article 23 (respect for home and family) and Article 19 (living independently and being included in the community).

In 2017, the U.N. Committee on the Rights of Persons with Disabilities adopted General Comment No. 5, stating that, for children, the right to community integration entails a right to live and grow up with a family. The Committee stated that placement in a family-like residence and group home is not a substitute for the right to a family under the CRPD. The protections established in the CRPD are consistent with new research revealing that institutions and residential care are inherently detrimental to children. Experience shows that all children, no matter how severe their disability, can and should receive the support and protection they need to live and grow up with a family. This article makes the case that the protections recognized by the CRPD apply to all children – not just children with disabilities. To implement this right, governments are under an obligation to create the range of supports needed so that all children can live in families and not institutions, residential care, or group homes. Protections for the family under the CRC should reflect these developments in international law and knowledge about child development. Article 41 of the CRC recognizes evolving international standards for the protection of children. Thus, the Committee on the Rights of the Child should update General Comment No. 9 to comply with new 2019]

legal standards that protect the right of all children to live and grow up with a family. The U.N. Guidelines for Alternative Care can be preserved, so long as they are used in a manner consistent with the requirements of the CRPD and are not used to justify permanent placement in group homes or other residential facilities.

#### INTRODUCTION

Throughout the world, millions of children are raised without a family in orphanages or other institutions.<sup>1</sup> The vast majority of these children have at least one living parent or extended family. Many parents who would want to keep their children have no choice but to give them up because of poverty—or because medical or social service authorities tell them that their children would be better off in institutions. Instead of protecting and supporting families, some social service systems break up families because of misperceptions about the ability of children or parents with disabilities to live safely together in the community. Despite these many forces that lead to the break-up of families, there is a growing international consensus that placement in any form of institution can be dangerous to children's psychological and intellectual development.<sup>2</sup> Such placement also increases the risk that children will be subject to abuse, exploitation, and trafficking.<sup>3</sup>

As this article will describe, some international standards for the care and treatment of children send a

<sup>&</sup>lt;sup>1</sup> The prevalence and factors contributing to the placement of children in institutions are described further in Part I of this article.

<sup>&</sup>lt;sup>2</sup> Part II of this article summarizes lessons from research and practice.

<sup>&</sup>lt;sup>3</sup> See infra note 63 and accompanying text (describing the findings of the U.N. Special Rapporteur on Torture that institutional placement puts children at increased risk of abuse and torture). In addition, in June 2018, the U.S. Department of State's Trafficking in Persons Report found that "[t]he physical and psychological effects of staying in residential institutions, combined with societal isolation and often subpar regulatory oversight by governments, place these children in situations of heightened vulnerability to human trafficking." U.S. DEPARTMENT OF STATE, TRAFFICKING IN PERSONS REPORT 22 (2018).

message to governments, service providers and families that placement in institutions or residential care—especially for children with disabilities—is not only acceptable but necessary. Unfortunately, differing provisions of international human rights law have established conflicting standards that add to this confusion. This article compares the requirements of the U.N. Convention on the Rights of the Child (CRC),<sup>4</sup> adopted in 1989, and the U.N. Convention on the Rights of Persons with Disabilities (CRPD), which entered into force in 2008.<sup>5</sup>

The CRC has long been interpreted to allow and encourage governments to maintain a system of residential care, including placement of children in group homes. The CRPD, in contrast, does not allow for the placement of children in institutions. As described in this article, recent interpretations by the U.N. Committee on the Rights of Persons with Disabilities over the last two years makes clear that placement in residential care, group homes or familylike residences violates the right of children to live and grow up with a family.<sup>6</sup> In March 2019, the U.N. Special

<sup>&</sup>lt;sup>4</sup> Convention on the Rights of the Child, Nov. 20, 1989, G.A. Res. 44/25, 1577 U.N.T.S. 3 [hereinafter CRC].

<sup>&</sup>lt;sup>5</sup> Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, G.A. Res. 61/106, Annex 1, U.N. Doc. A/61/49 [hereinafter CRPD].

<sup>&</sup>lt;sup>6</sup> Recent developments in this area are discussed in text accompanying notes 38-41 infra. The Committee on the Rights of Persons with Disabilities is established under article 34 of the CRPD and its functions are set forth in articles 35 through 39. The Committee's power to make "general recommendations" to States Parties under article 39 authorizes it to adopt General Comments, which, "with their elucidation of specific treaty provisions, serve to guide the practice of states parties with respect to the panoply of rights-related issues that have an impact on persons with disabilities." Mary Pat Treuthart, Article 39 Report of the Committee, in The U.N. CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: A COMMENTARY 1119 (Ilias Bentkas et al. eds., 2018) [hereinafter CRPD COMMENTARY]. General Comments adopted by a treaty-based body are generally considered authoritative but not binding interpretations. See Kerstin Mechlem, Treaty Bodies and the Interpretation of Human Rights, 42 VAND. J. TRANSN'L L. 905, 929-30 (2009) (describing the legal significance of treaty bodies and the General Comments they adopt). While there are differing views as to the legal weight that should be accorded to General Comments, many commentators believe the Committee constitutes "the most authoritative interpreter of the treaty it monitors and . . . states parties are not free to disregard a treaty body's

Rapporteur on Disability called for the enforcement of the stronger CRPD standards by protecting the right of children to grow up in a family.<sup>7</sup> As described in Part II, these protections are consistent with recent findings concerning child welfare that it is inherently detrimental to raise any child outside the care of a family.

For children in institutions or at risk of being placed outside a family, it is urgent to establish a common understanding of the rights of children under the CRC and the CRPD. This article describes how the protection of families is an objective of both the CRC and the CRPD, and makes the case that the right to family should be seen as a concept under unifying international law. As the international community celebrates the thirtieth anniversary of the CRC, it is now time to reexamine the way the CRC is used and interpreted in light of new understandings of child development, lessons learned from the disability movement, and protections recognized by the CRPD.

The right to a family for both children and parents has long been recognized as a matter of international human

interpretation with which they disagree, despite its nonbinding nature." Id. at 929.

<sup>&</sup>lt;sup>7</sup> Report of the Special Rapporteur on the Rights of Persons with Disabilities. Catalina Devandas, Rights of persons with disabilities ¶19, U.N. Doc. A/HRC/40/54 (2019) [hereinafter 2019 Special Rapporteur on Disability Report]. While the Human Rights Council has not referenced the CRPD's position on residential care or group homes, it has adopted the CRPD standard for the protection of the family by resolution. See Rights of the child: empowering children with disabilities for the enjoyment of their rights, including through inclusive education, Hum. Rts. Council, 40th sess., ¶16, U.N. Doc. A/HRC/40/L.20/Rev.1 (2019) (urging states to "replace institutionalization with appropriate measures to support family and community-based services and, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family and, failing that, within the community in a family setting"). This language tracks Article 24(5) of the CRPD and does not leave room for placement of children in "suitable institutions" as allowed for under the CRC. See discussion in Part III infra.

rights law.<sup>8</sup> Article 16 of the 1948 Universal Declaration of Human Rights states that "family is the natural and fundamental group unit of society and is entitled to protection by society and the State."<sup>9</sup> When it was adopted in 1989, the CRC recognized the fundamental principle that children "should grow up in a family environment ...."<sup>10</sup> The CRC's preamble—one of the main sources for determining the overriding purpose of the convention<sup>11</sup>—calls for "protection and assistance" of the family "for the well-being of all its members and particularly children."<sup>12</sup> The CRC's protections for the family appear in a number of interrelated provisions of the convention.<sup>13</sup>

Despite the strong support for family under the CRC, the convention includes provisions that have been used or interpreted to limit the right of all children to live and grow up with a family. CRC Article 20 provides that, if a child is "temporarily or permanently deprived of his or her family,"

<sup>9</sup> Universal Declaration of Human Rights art. 16, Dec. 10, 1948, G.A. Res. 217A(III), U.N. Doc. A/810 at 71 (1948) [hereinafter UDHR].

 $^{10}$  CRC, supra note 4, pmbl.

<sup>11</sup> See Vienna Convention on the Law of Treaties art. 31(1), May 23, 1969, 1155 U.N.T.S. 331, 340 ("A treaty shall be interpreted in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in the light of its object and purpose."). The preamble is part of the "context for the purpose of the interpretation of a treaty." *Id.* art. 31(2).

<sup>12</sup> CRC, *supra* note 4, pmbl.

<sup>13</sup> See, e.g., *id.* art. 7.1 (establishing that the child has the "right to know and be cared for by his or her parents"); art. 9.1 ("a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review" determine that "separation is necessary for the best interests of the child" for such reasons as "abuse or neglect of the child by the parents"); art. 16 ("No child should be subject to arbitrary or unlawful interference with his or her privacy, family, [or] home . . .").

<sup>&</sup>lt;sup>8</sup> See RACHEL HODGIN & PETER NEWELL, UNICEF, IMPLEMENTATION HANDBOOK ON THE CONVENTION ON THE RIGHTS OF THE CHILD 122 (2007) (describing the history and the development of the right to family) (hereinafter UNICEF IMPLEMENTATION HANDBOOK); International Covenant on Civil and Political Rights art. 23(1), Dec. 16, 1966, G.A. Res. 2200A (XXI), 999 U.N.T.S. 171 (1967) [hereinafter ICCPR]; International Covenant on Economic, Social and Cultural Rights art. 10, Dec. 16, 1966, G.A. Res. 2200A (XXI), 993 U.N.T.S. 3 (1967) [hereinafter ICESCR]. Both recognize that "[t]he family is the natural and fundamental group unit of society" and is entitled to protection by society and the State. ICCPR, *supra*, art. 23(1); ICESCR, *supra*, art. 10.

that child may receive care in "foster placement . . . adoption or if necessary placement in suitable institutions for the care of children."<sup>14</sup> The Office of the U.N. High Commissioner on Human Rights observed that the CRC's provisions for placing children in "suitable institutions" is based on assumptions commonly held at the time the convention was drafted that some children, especially children with disabilities, would inevitably have to remain in institutions.<sup>15</sup>

The CRC is the first international treaty to explicitly extend its protections to children with disabilities.<sup>16</sup> Despite this advance, CRC Article 23 on children with disabilities has significant limitations. Article 23 calls on governments to provide children with "special care" that is "conducive to the child's achieving the fullest possible social integration . . . ."<sup>17</sup> Rather than calling on society to adapt to be fully inclusive of children with disabilities, reference to the "fullest possible" allows for the interpretation that full integration might not be possible for some children.<sup>18</sup>

The CRC has been criticized by the disability

<sup>&</sup>lt;sup>14</sup> CRC, *supra* note 4, art. 20(1) ("A child temporarily or permanently deprived of his or her family environment or in whose own best interest cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State."); art. 20(3) ("Such care could include, *inter alia*, foster placement, *kafalah* under Islamic law, adoption or if necessary placement in suit able institutions for the care of children.").

<sup>&</sup>lt;sup>15</sup> See discussion in text accompanying note 230 *infra* (noting description by Dr. Dainius Puras, writing on behalf of the U.N. Office of the High Commissioner for Human Rights in 2011, that CRC Article 20 is based on out-dated assumptions that children would inevitably have to remain in institutions). U.N. Special Rapporteur Catalina Devandas has also expressed concerns about CRC Article 20 and called for its review. See text accompanying note 231 *infra*.

<sup>&</sup>lt;sup>16</sup> Article 2(1) of the CRC is the first treaty-based protection against discrimination to explicitly mention disability as a protected class. See U.N. Comm. on Rts of Child, General Comment No. 9: The rights of children with disabilities ¶¶2, 47, U.N. Doc. CRC/C/GC/9 (2007) [hereinafter General Comment No. 9] (describing the rights of children with disabilities under the CRC).

<sup>&</sup>lt;sup>17</sup> CRC, *supra* note 4, art. 23(3).

<sup>&</sup>lt;sup>18</sup> Dr. Ursula Kilkelly has also raised concerned that the protection of the right to live in the community under CRC Article 23 is not as absolute as other provisions of the CRC, such as the Article 19 obligation of States Parties to prevent child abuse. *See* discussion in text accompanying notes 226-28 *infra*.

community for its "medical model" approach, appearing to assume that "a biologically anomalous child should be cured or repaired to fit social expectations rather than that social conventions ought to be adjusted to include children with disabilities."<sup>19</sup> In addition, CRC Article 23 merely states that governments "should" (rather than "shall") create necessary social services (unlike other parts of the CRC which clearly use obligatory language).<sup>20</sup>

The language of the CRC has led some leading child's rights experts to believe that the Convention establishes only a "policy objective of securing a family-based placement wherever possible and appropriate."<sup>21</sup> From this perspective, "[i]t is thus wise to disregard any so-called 'right to family' argument in promoting deinstitutionalization; embracing the recognized policy objective of securing a family-based placement wherever possible and appropriate is a far sounder basis on which to proceed."<sup>22</sup> Other authorities, such as the Inter-American Commission on Human Rights (IACHR), have looked to the CRC, as well as the American Convention, and seen the value of a right to family as a basis

<sup>&</sup>lt;sup>19</sup> Kjersti Skarstad & Michael Ashley Stein, *Mainstreaming disability in the United Nations treaty bodies*, 17 J. HUM. RTS. 1.3 (2018). *See also* Janet E. Lord, *Child Rights Trending: Accommodating Children with Disabilities in the Global Human Rights Framework and U.S. Foreign Policy*, 16 WHITTIER J. CHILD AND FAMILY ADVOCACY, 1, 3 (2017) ("Article 23 of the CRC emphasizes 'special care' as opposed to reasonable accommodations and other accessibility measures that remove barriers and encourage full participation in society. The CRC does not address the various issues which lie at the center of a progressive disability rights approach for children."). Rosemary Kayess, now a member of the U.N. CRPD Committee, has observed that references to "special care" for children with disabilities "ultimately derives from a medical model of disability, and its application only to 'mentally and physically disabled' children." Rosemary Kayess & Phillip French, *Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities*, 8 HUM. RTS. L. REV. 1, 13 (2008).

<sup>&</sup>lt;sup>20</sup> See Ilias Bantekas, Article 7 Children with Disabilities, in CRPD COMMENTARY, supra note 6, at 198, 201 (comparing the protections in the CRC and CRPD).

<sup>&</sup>lt;sup>21</sup> Nigel Cantwell, *The Human Rights of Children in the Context of Formal Alternative Care, in* ROUTLEDGE INTERNATIONAL HANDBOOK OF CHILDREN'S RIGHTS STUDIES 257, 269 (Wouter Vandenhole et al. eds., 2015).

 $<sup>^{22}</sup>$  Id.

for "[e]nding Institutionalization in the Americas."<sup>23</sup> Despite recognizing these valuable principles, however, the IACHR "Right to Family" report in 2013 unquestioningly accepts the many limitations on the right to family spelled out in the CRC's General Comments and fails to account for the important developments under the CRPD.

Implementation of the CRC's provisions on alternative care has been guided by General Comment No. 9, adopted in 2006 by the Committee on the Rights of the Child, to define the application of the CRC to children with disabilities.<sup>24</sup> General Comment No. 9 calls for the "transformation" of institutions into smaller residential homes, but it does not require that children live and grow up with a family.<sup>25</sup> General Comment No. 9 does call for limiting any placement in an institution to the "last resort."

One the one hand, true enforcement of the "last resort" standard would greatly curtail placement for millions of children around the world who are now raised in orphanages

<sup>&</sup>lt;sup>23</sup> See Inter-Am. Comm. Hum. Rts., The Right of Boys and Girls to a FAMILY. ALTERNATIVE CARE. ENDING INSTITUTIONALIZATION IN THE AMERICAS 7 (2013) (calling for enforcement of "the child's right to live in and be raised by his or her family"). In the preface to that report, Marta Santos Pais, Special Representative of the United Nations' Secretary General on Violence Against Children and Rosa María Ortíz, Commissioner and Rapporteur on the Rights of the Child of the IACHR, state that "one of the States' duties, which is imperative to reflect in the National Systems for the Promotion and Protection of Children's Rights, is to ensure the right of the child to be raised in his or her family and community environment." Id. at vi. They cite the importance of a report that "urges the States to end the institutionalization of children through a planned process permitting adequate care in response to the needs of protection and the best interests of children." Id. at vii. The Inter-American Court has also recognized an enforceable right of children to live with his or her family. See Juridical Status and Human Rights of the Child, Inter-Am. Ct. H.R., OC-17/02, Aug. 28, 2002 (Ser. A) No. 17, ¶ 71. In this non-binding advisory opinion, the Court goes on to say that "[e]very minor child has the right to the measures of protection required by his condition as a minor on the part of his family, society, and the state." Id.

<sup>&</sup>lt;sup>24</sup> The main guidance to the requirements of the CRC with regard to children with disabilities was adopted in 2006. *See* General Comment No. 9, *supra* note 16. *See also* discussion in text accompanying notes 234-245 *infra*.

 $<sup>^{25}</sup>$  The limitations of General Comment No. 9 are described further in Part IV of this article.

out of a perception that this is the best and safest place for them. Many orphanages make no pretense of trying to keep children with their families, and many countries fund institutions without the creation of family support systems or foster care. Progressive as the "last resort" standard may be in some contexts, this article describes ways that the same approach can be an obstacle to true reform. In practice, limiting placement to the last resort provides little meaningful protection to children when community-based services and supports for children to live with families are inadequate. In countries where there are few services and protections for children with disabilities, allowing placement as a "last resort" leaves children with disabilities largely unprotected.

The most detailed standards for the implementation of the CRC's protections under Article 20 are the U.N. Guidelines for Alternative Care of Children (the Guidelines).<sup>26</sup> The Guidelines were "welcomed" by the U.N. Human Rights Council on June 17, 2009 and transmitted for "consideration with a view to their adoption" by the U.N. General Assembly.<sup>27</sup> As in CRC Article 23, much of the language of the U.N. Guidelines describe what States "should" do rather than "must" do, and they were never intended to represent binding standards.<sup>28</sup>

The Guidelines have a strong emphasis on protecting families to avoid placement of children in institutions, and they encourage governments to create the support services

 $<sup>^{26}</sup>$  Guidelines for the Alternative Care of Children ¶ 22, G.A. Res. 64/142, U.N. GAOR, 64th sess., U.N. Doc. A/RES/64/142 (2010) [hereinafter U.N. Guidelines]. See discussion of Guidelines in text accompanying notes 248-258 infra.

<sup>&</sup>lt;sup>27</sup> Guidelines for the Alternative Care of Children, Res. 11/7, Hum. Rts. Council, 11th sess. 27th mtg. (2009). *See generally* NIGEL CANTWELL, ET AL., CENTRE FOR EXCELLENCE FOR LOOKED AFTER CHILDREN IN SCOTLAND, MOVING FORWARD: IMPLEMENTING THE GUIDELINES FOR THE ALTERNATIVE CARE OF CHILDREN 43 (2012) (describing the background, drafting, and meaning of the Guidelines [hereinafter IMPLEMENTING THE GUIDELINES].

<sup>&</sup>lt;sup>28</sup> Implementing the Guidelines, *supra*, at 20.

that would make this possible.<sup>29</sup> The Guidelines state that "alternatives should be developed" to institutions to bring about their "progressive elimination."<sup>30</sup> Despite this, the Guidelines also encourage governments to create and maintain a system of "residential care facilities" where children can receive "individualized and small-group care" in a "quality" environment.<sup>31</sup>

An entirely new approach to equal protection and the right to family is established under CRPD. During the CRPD's drafting process, disability rights and children's rights activists sought more effective recognition of the right to family based on perceived limitations of the CRC's protections.<sup>32</sup> Under the CRPD, protections for the right of children to grow up with a family derive from Article 19 ("living independently and being included in the community") and Article 23(5) ("respect for home and the family"). Article 23(5) states that, "where the immediate family is unable to care for a child with disabilities [States Parties shall undertake every effort to provide alternative care within the wider family and failing that within the community in a family setting." Article 23 does not allow for placement in institutions-"suitable" or otherwise.

The language of Article 23 includes the words "undertake every effort," which could be interpreted to mean that the provision is not meant to create an absolute right to family for all children. Article 23 is certainly a recognition that full implementation of this right will take "effort." The creation of family support systems, foster care, and child protection systems will be essential to ensure that children

<sup>&</sup>lt;sup>29</sup> U.N. Guidelines, *supra* note 26, ¶ 3 ("The family being the fundamental group of society . . . . [t]he State should ensure that families have access to forms of support in the caregiving role.").

 $<sup>^{30}</sup>$  Id. ¶ 23.

 $<sup>^{31}</sup>$  Id.

<sup>&</sup>lt;sup>32</sup> See Ilias Bantekas, Article 7: Children with Disabilities, in CRPD COMMENTARY, supra note 6, at 204 (concluding based on review of the traveaux of the CRPD drafting process that "[i]n general, NGO's strongly believed that neither article 23 CRC nor draft article 16 effectively addressed the rights of disabled children").

are not left in abusive situations or simply thrown out onto the streets. But when those services are not in place, Article 23 is clear that placement must still be within a "family setting."

As Part III of this article explains, the CRPD recognizes the importance of progressive realization of rights when planning and investment is needed in social service system reform.<sup>33</sup> The principle of progressive realization does *not* mean that governments are any less obligated to take immediate action to bring about full enforcement to the extent possible.

As this article will describe, CRPD Article 23 cannot be understood in isolation. It must be understood along with Article 19, which provides even stronger protections for the right to community integration. And when taken together, it is clear that a "family setting" must be understood as a family or family-based care (such as extended kinship care or foster care) and *not* as residential care, placement in a group home, or any kind of "family-like" care.<sup>34</sup>

Article 19 recognizes that all people with disabilities have a right to live in the community with choices equal to others. Article 19 has been described as "a foundational platform for all other rights" because "a precondition for anyone to enjoy all their human rights is that they are within and among the community."<sup>35</sup> Article 19 is sweeping in its breadth and universal in its commitment to integration as it applies to *all* people with disabilities—no matter the type or severity of their disability.<sup>36</sup> Article 19 is unlike the CRC and

<sup>&</sup>lt;sup>33</sup> See note 214 *infra* and accompanying text (noting description by Professor Quinn and others of how placement in residential programs cannot be considered a form of "progressive enforcement" for the right to community integration).

<sup>&</sup>lt;sup>34</sup> See note 40 infra and accompanying text.

<sup>&</sup>lt;sup>35</sup> COUNCIL OF EUROPE COMMISSIONER FOR HUMAN RIGHTS, THE RIGHT OF PEOPLE WITH DISABILITIES TO LIVE INDEPENDENTLY AND BE INCLUDED IN THE COMMUNITY 4 (2012) [hereinafter RIGHT TO LIVE INDEPENDENTLY].

 $<sup>^{36}</sup>$  U.N. Comm. on Rts. of Persons with Disabilities, General Comment No. 5 on living independently and being included in the community  $\P\P$  20-21, U.N. Doc. CRPD/C/GC/5 (2017) [hereinafter General Comment No. 5]. General Comment No. 5 states that: "Persons with intellectual disabilities, especially those with

previous disability standards that ensured community integration only "as far as possible," and therefore left open the possibility that some people are not capable of full integration.<sup>37</sup>

The U.N. Committee on the Rights of Persons with Disabilities has contributed greatly to the understanding of the requirements of CRPD Article 19 in its General Comment No. 5, adopted in August 2017.<sup>38</sup> While the General Comment is non-binding, it provides authoritative guidance on the meaning and requirements of CRPD Article 19.<sup>39</sup> In General Comment No. 5, the CRPD Committee explains how the right of children to community integration carries with it a different set of State obligations than it does for adults: "[f]or children, the core of the right to live independently and be included in the community entails a right to grow up in a family."<sup>40</sup>

To enforce the "core" right to grow up in a family, the CRPD Committee states that:

<sup>39</sup> See note 6 supra (discussing source of authority for General Comments adopted by the Committee on the Rights of Persons with Disabilities).

complex communication requirements, inter alia, are often assessed as being unable to live outside of institutionalized settings. Such reasoning is contrary to article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirement." *Id.* ¶ 21.

<sup>&</sup>lt;sup>37</sup> With regard to people with psychosocial disabilities, for example, the most authoritative standard before the CRPD was the U.N. Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (the "MI Principles"). The MI Principles recognize that "[e]very person with a mental illness shall have the right to live and work, as far as possible" in the community. See Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, G.A. Res. 119, U.N. GAOR, 46<sup>th</sup> Sess., Supp. No. 49 Annex, at 188-92, U.N. Doc. A/46/49 (1991). See also Eric Rosenthal & Leonard S. Rubenstein, International Human Rights Advocacy under the "Principles for the Protection of Persons with Mental Illness," 16 INT'L J. LAW & PSYCHIATRY 257, 262 (1993) (describing the inherent tensions in the MI Principles that are "an inevitable conflict between the desire to treat and the libertarian desire to leave someone alone").

<sup>&</sup>lt;sup>38</sup> General Comment No. 5, *supra* note 36, ¶ 6 (explaining obligations under CRPD Article 19 and that the general comments are intended to help with "the implementation of the Convention across all articles").

<sup>&</sup>lt;sup>40</sup> General Comment No. 5, *supra* note 36, ¶ 37 (emphasis added).

Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. 'Family-like' institutions are still institutions and are no substitute for care by a family.<sup>41</sup>

Taken together, CRPD Articles 19 and 23(5) establish that nothing other than a family can constitute a home, and denial of the opportunity to live and grow up with a family violates the CRPD. The U.N. Special Rapporteur on Disability, Catalina Devandas, has strongly endorsed these findings and builds on this analysis in her 2019 report:

> The detrimental effects on child development of the placement of a child in any residential institution, even in small residential homes or "family-like" institutions have been vastly demonstrated. Any placement of children in a residential setting outside a family must be considered placement in an institution and subject to the protections against deprivation of liberty.<sup>42</sup>

Relying on this Special Rapporteur's analysis, any placement that deprives a child of the right to live with family constitutes placement in an institution, so residential care programs and group homes should also be considered another form of "institution."

General Comment No. 5 is consistent with a growing body of research that shows that group residential care in large or small residential facilities is detrimental to the growth, development, and well-being of children—regardless

<sup>&</sup>lt;sup>41</sup> *Id.* ¶ 16(c).

 $<sup>^{42}</sup>$  2019 Special Rapporteur on Disability Report, supra note 7,  $\P$  19.

of staffing levels and quality of care.<sup>43</sup>Among the broad array of dangers to children and adolescents, group care based on rotating staff does not allow for the establishment of permanent emotional bonds that can only develop in the context of a family—even for children with significant behavioral difficulties.<sup>44</sup> After a comprehensive review of the research literature to date, an international consensus statement adopted by researchers on child welfare concluded that "[g]roup settings should not be used as living arrangements, because of their *inherently detrimental* effects on the healthy development of children, regardless of age."<sup>45</sup>

If family-based support systems are unavailable, governments are under the obligation to create them, as described in detail in General Comment No. 5. To the extent that the creation of services are subject to the principle of "progressive enforcement" of rights, as this article will describe, these rights can still be enforceable and can still entail an obligation for a broad array of immediate actions. The CRPD was drafted so that protections were clearly "framed and recognized *as rights*, not merely as state duties or general undertakings."46 Don MacKay, New Zealand's Representative at the United Nations and Chair of the U.N. Ad Hoc Committee that negotiated the Convention from 2005 onwards, stated that the CRPD "marks a 'paradigm' shift from thinking about disability as a social welfare matter to dealing with it as a human rights issue, which acknowledges that societal barriers and prejudices

<sup>&</sup>lt;sup>43</sup> Mary Dozier et al., Consensus Statement on Group Care for Children and Adolescents: A Statement of Policy of the American Orthopsychiatric Association, 84 AM. J. ORTHOPSYCHIATRY 219-225 (2014). See discussion in Part III infra.

<sup>&</sup>lt;sup>44</sup> *Id.* at 220.

<sup>&</sup>lt;sup>45</sup> Id. at 219 (emphasis added).

<sup>&</sup>lt;sup>46</sup> Tara J. Melish, An Eye Toward Effective Enforcement: A Technical-Comparative Approach to the Drafting Negotiations, in HUMAN RIGHTS AND DISABILITY ADVOCACY 70, 81 (Maya Sabatello & Marianne Schulze eds., 2014). As described by Professor Tara Melish, who represented DRI before the U.N. Ad Hoc Committee drafting the CRPD, one of the goals of the drafters was to avoid such "paternalistic language and inappropriate qualifiers on rights such as 'endeavor to' and 'to the extent possible." Id. at 80.

themselves are disabling."47

To understand the full meaning of CRPD Articles 19 and 23 together, it is important to understand that the CRPD is grounded in what is called a "social" model of disability rather than a medical or welfare model.<sup>48</sup> Instead of allowing real or perceived impairment to hold a person back from exercising their rights or participating in society, this new anti-discrimination framework requires society to be made accessible to bring about rights protection and full inclusion.<sup>49</sup> Instead of looking to see whether a child is too disabled to live in society as part of a family (or whether a parent is capable of keeping his or her children) the CRPD requires society to become accessible by providing the support necessary to allow that child to live and grow up in a family.

The framework for legal enforcement using this social model of disability provides a more effective way of protecting both children and parents from denial of the right to a family. The CRPD framework provides an avenue for challenging the limitations of previous standards that allow placement of children in institutions as "a last resort." Given the evidence that all children *can* be integrated into families with appropriate support, placement as a last resort implicitly places the responsibility or blame on the child for not being able to fit in or take advantage of existing support

<sup>&</sup>lt;sup>47</sup> Don MacKay, *The United Nations Convention on the Rights of Persons with Disabilities*, 34 SYRACUSE J. INT'L L. & COM. 323, 328 (2007). *See also* Kayess, *supra* note 19, at 3; ARLENE S. KANTER, THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW 8, 31 (2017) (discussing the paradigm shift brought about by the CRPD).

 $<sup>^{48}</sup>$  As recognized in the preamble of the CRPD, the social model of disability derives from the understanding that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on a basis with others." CRPD, *supra* note 5, pmbl. ¶ e. Part III of this article describes the social model of disability and its implications.

<sup>&</sup>lt;sup>49</sup> The CRPD notably does not define disability but explains in its preamble "that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society." CRPD, *supra* note 5, pmbl. ¶ e.

systems. If a child is placed in an institution or residential care program as a last resort because social service systems lack the support that a child needs to live with a family in the community, the CRPD would require society to accommodate. Investments in residential care and group homes are not the "special care" needed by children. On the contrary, they can be understood as the barriers faced by children to living full lives in the community with the family they need to grow and thrive.

As this article will describe, the protections established in the CRPD have implications for *all* children, not just children with disabilities.<sup>50</sup> The key language of CRPD General Comment No. 5 applies to "children" and not just children with disabilities. Article 23(4), which states that "[i]n no case shall a child be separated from parents on the basis of a disability either of the child or one or both of the parents." CRPD Article 23(4) protects "children" (and not just "children with disabilities") from family separation if their parents are disabled or wrongly perceived to be unable to keep their children. Instead of breaking up the family, the CRPD requires support for the family. By protecting both the child and the parents from discrimination, the CRPD assures the enforcement of the right to live and grow up with a family for *all* children.

Against the background of protections afforded under the CRPD, Part IV reviews the protections and

Despite their intentions, however, I argue that the CRPD includes new interpretations and applications of existing rights as well as a new approach to human rights treaty enforcement. For this reason, the CRPD is significant not only to people with disabilities but also to the development of international human rights more generally, by offering new human rights protections for all people, with and without disabilities.

KANTER, supra note 47, at 49.

<sup>&</sup>lt;sup>50</sup> See discussion in Part III-A *infra* (describing the application of CRC Articles 19 and 23 to children with and without disabilities) and Part VII on the indivisibility of human rights. Professor Arlene Kanter has described how the CRPD has implications beyond people with disabilities even though it was drafted specifically to protect this population—without creating any new rights:

interpretations of the CRC and demonstrates how they fall short of newer CRPD provisions. Both the CRC and the CRPD protect families, but the CRPD provides a stronger, broader, and more unequivocal protection of that right. This article takes the position that the strengthened protections for the right of children to live and grow up in the family, now recognized under the CRPD, can be used to reinterpret article 20 of the CRC. Such a reinterpretation will more effectively achieve the goal set out in the CRC's preamble of ensuring that children grow up with the love and care of a family.

Part V of this article examines lessons learned and opportunities the horizon on through regional implementation. This author's personal observations about reforms in the Republic of Georgia demonstrates the dangers of and limitations of traditional approaches to reform. In the absence of community-based support for families and children with disabilities, the Georgia experience shows how placement of children in group homes can easily become the norm, resulting in a new generation of smaller institutions for children. Part V also examines the experience of Disability Rights International (DRI) efforts to promote a right to community integration through the Inter-American human rights system. By viewing institutional placement as a form of discrimination, there is great promise in using regional human rights principles to legally enforce a right to community integration.

Part VI of this article examines the right of children and families to participate in decisions that affect them. The right to choice and the evolving capacities of children are important principles established in the CRC and CRPD. A closer examination of the law reveals that neither the CRC nor CRPD provide an absolute right to choice for children. Where they face serious dangers that they may not understand, the duty to protect children from harm must also be taken into account. And more importantly, when children have never had a true opportunity to live and grow up in a safe and stable family, they have never been given a real choice as to how they would like to grow up. Social service authorities may be deceiving themselves in believing that such children are "choosing" residential care in any meaningful way. Of course, children's capacities evolve at different ages, and at some point, fundamental choices of older adolescents must be fully respected.

Part VII of this article examines the conflict between CRC and CRPD interpretations within the bigger picture of human rights. A core principle of human rights law is that all rights are indivisible and interdependent. Rather than seeing CRC and CRPD rights as in competition with each other, this article argues that children are best protected when both systems are viewed as part of a common whole. As a legal matter, both conventions recognize that human rights law evolve and the strongest protections for all children must be recognized. As a practical matter, the lessons learned from research on child welfare show that the dangers facing children in group care are much the same, whether or not they are labelled with a disability.

Social service systems that do not allow children to live and grow up with families are themselves barrier to full social and community integration for children with and without disabilities. If disability is indeed a social construct, as it is now commonly understood, then residential care and group homes should themselves be understood as "disabling" for all children—leaving them without the opportunity to live and grow up in a family as experienced by all other children.

As the international community celebrates the thirtieth anniversary of the adoption of the CRC and the tenth anniversary of the U.N. Guidelines, now is the time to update international standards and ensure that practice in the children's rights field complies fully with the CRPD. To provide guidance to governments on implementing these rights, the Committee on the Rights of the Child should review and update General Comment No. 9, drafting a new standard that conforms to both the CRC and the CRPD. The U.N. Guidelines for Alternative Care of Children contain much valuable language and they should be preserved and

strengthened, but they must also conform to the requirements of the CRPD, which do not allow for placement in institutions or residential care. To improve guidance for governments, donors, service providers, and activists, it will be essential for the U.N. Committee on the Rights of the Child and other human rights authorities to clarify how governments should fully protect the right of *all* children to live and grow up in a family.

## I. MODERN CONTEXT: THE WORLDWIDE PROBLEM OF INSTITUTIONALIZATION

It is commonly estimated that there are at least eight million children who reside in orphanages or institutions around the world.<sup>51</sup> If all residential homes come to be understood as another form of institutionalization, as

<sup>&</sup>lt;sup>51</sup> It is difficult to determine exactly how many children are placed in institutions around the world. Estimates vary, and part of the difficulty in coming up with an exact number is linked with confusion about what exactly is an "orphanage" or an "institution" or "residential care." The estimate of eight million children in institution that is widely used is cited in U.N. documents that never exactly address this issue. See Rights of the Child: Note by the Secretary-General ¶ 55, U.N. Doc. A/61/299 (2006) (estimating the number of children in "institutions" at eight million children worldwide). See also UNICEF IMPLEMENTATION HANDBOOK, supra note 8, at 283. According to Save the Children, however, "[t]he actual figure is likely to be much higher, due to the proliferation of unregistered institutions and the lack of data on vulnerable children." SAVE THE CHILDREN, KEEPING CHILDREN OUT OF HARMFUL INSTITUTIONS: WHY WE SHOULD BE INVESTING IN FAMILY-BASED CARE 3-4 (2009). There are also studies showing that as few as 2.7 million children may be confined to institutions and residential facilities. See Nicole Petrowski et al., Estimating the number of children in formal alternative care: challenges and results, 70 CHILD ABUSE & NEGLECT 388-298 (2017). The UNICEF website cites this study but adds a caveat: "At least 2.7 million children are living in residential care, but this is the tip of the iceberg." UNICEF, Children in Alternative Care (July 2017), available at https://data.unicef.org/topic/child-protection/children-alternativecare/ (visited Apr. 12, 2018). This more recent estimate revises downward the number of children in institutions, but the study itself recognizes that there are methodological problems in defining institutions, including the problem of relying on inconsistent government data. It is worth noting that there have also been studies estimating the number of children in institutions to be as high as 10 million. See MINISTRY FOR FOREIGN AFFAIRS SWEDEN, CHILDREN IN INSTITUTIONS: INTERNATIONAL Development COOPERATION, 2001,available at <a>http://www.government.se/contentassets/42b806a7f8b-046468116e4f1245428</a> b5/children-in-institutions>.

recommended by the U.N. Special Rapporteur on Disability, the number of children in institutions around the world would be understood to be vastly higher.

In practice, the vast majority of children placed in institutions or orphanages are not orphans. Estimates vary by country, but some 80-98% of children placed in orphanages have at least one living parent.<sup>52</sup> The majority of children are placed in institutions because of poverty or disability.<sup>53</sup> Children are also placed in institutions because of a lack of accessible healthcare, habilitation, social support services, or education in the community.<sup>54</sup> As described by the U.N. Special Rapporteur on Disability, "[p]eople with disabilities are regularly deprived of their liberty to access services that should have been delivered in the community."55 And when children receive the protection and support they need to live and grow up with a family, experience has shown that it is possible to reduce and eliminate orphanages and other institutions for children.<sup>56</sup> If a child's parents are unable to care for them, numerous alternatives can be made available to ensure that a child can live and grow up with a family, including extended kinship care, substitute family care, foster care, or adoption.<sup>57</sup> It was

<sup>&</sup>lt;sup>52</sup> See, e.g., LUMOS, IN OUR LIFETIME: HOW DONORS CAN END THE INSTITUTIONALIZATION OF CHILDREN 12 (2015) (estimating the number of children with parents at least 80%); see also RICHARD CARTER, FAMILY MATTERS: A STUDY OF INSTITUTIONAL CHILDCARE IN CENTRAL AND EASTERN EUROPE AND THE FORMER SOVIET UNION 1 (2005) (estimating the number of children with parents as high as 99%). In Europe, UNICEF has estimated that 95–98% of children in institutions have families. See UNICEF, TransMonEE Database (2012), available at http://www.transmonee.org/ (lvisited Mar. 9, 2018).

<sup>&</sup>lt;sup>53</sup> According to the U.N. Secretary-General's Study on Violence against Children, "[a]s many as 8 million of the world's children are in residential care. Relatively few are in such care because they have no parents, but most are in care because of disability, family disintegration, violence in the home, and social and economic conditions, including poverty." UNICEF IMPLEMENTATION HANDBOOK, *supra* note 8, at 283. *See also* FAITH IN ACTION INITIATIVE, CHILDREN, ORPHANAGES, AND FAMILIES: A SUMMARY OF RESEARCH TO HELP GUIDE FAITH-BASED ACTION 6 (2014). Placement in institutions also results from parents experiencing financial difficulties, minorities facing discrimination, parents with disabilities or emotional difficulties, or single mothers—all of whom are often improperly blamed as inadequate or bad parents. UNICEF, CHILDREN IN INSTITUTIONS: THE BEGINNING OF THE END? v. (2003).

<sup>&</sup>lt;sup>54</sup> 2019 Special Rapporteur on Disability Report, *supra* note 7, ¶ 23.

<sup>&</sup>lt;sup>55</sup> *Id.* ¶ 30 (emphasis added).

<sup>&</sup>lt;sup>56</sup> See discussion and review of literature in Part II infra.

<sup>&</sup>lt;sup>57</sup> These options are further described in Part II-C of this article.

once believed that some children with disabilities would have to be confined to institutions or placed in some form of residential care. But experience now shows that, with appropriate support, children with "every kind and severity of impairment [are] currently living successfully with a family."<sup>58</sup>

Scientific child research on development is supplemented by the findings of advocacy and human rights organizations, like the one I lead—Disability Rights International (DRI)-showing that violence and abuse is serious and widespread in large and small institutions for children.<sup>59</sup> Research shows violence in institutions is nearly universal; institutions and group care can create a culture and "ecosystem" that breed violence and exploitation of children.60 Based on what researchers, human rights activists, and the disability community have learned about the danger of institutions and the importance of families, UNICEF in 2013 called for governments to "end the institutionalization of children."<sup>61</sup>

Protecting against placement in institutions is increasingly recognized as core to the prevention of violence and torture.<sup>62</sup> U.N. Special Rapporteur on Torture Juan E. Méndez took a strong stand against the detention of children, noting the "heightened risk" of violence and abuse and

<sup>&</sup>lt;sup>58</sup> NANCY ROSENAU, INSTITUTE ON COMMUNITY INTEGRATION, DO WE REALLY MEAN FAMILIES FOR ALL CHILDREN? PERMANENCY PLANNING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES 7 (2000); see also Arlene S. Kanter, Permanency Planning for Children with Disabilities: The Right to Live with a Family for Every Child, 28 CHILD LEGAL RTS. J. 1, 16 (2008).

<sup>&</sup>lt;sup>59</sup> DRI reports are available at www.DRIadvocacy.org.

<sup>&</sup>lt;sup>60</sup> A.K. Shiva Kumar et al., *Ending Violence in Childhood: A Global Imperative*, 22 PSYCH. HEALTH & MED. S1, 9 (2017).

<sup>&</sup>lt;sup>61</sup> UNICEF, THE STATE OF THE WORLD'S CHILDREN 46-47 (2013). Documentation from human rights organizations was incorporated into the findings of this report. *See* Eric Rosenthal & Laurie Ahern, *Perspective: Children in Institutions, in id.* at 46 (summarizing DRI's worldwide findings).

<sup>&</sup>lt;sup>62</sup> See Eric Rosenthal, A Mandate to End Placement of Children in Institutions and Orphanages: The duty of governments and donors to prevent segregation and torture, in PROTECTING CHILDREN AGAINST TORTURE IN DETENTION 303, 312-313 (2017) (describing the obligations under the CRC, CRPD and the Convention Against Torture to avoid unnecessary confinement of children in institutions and to create services and supports to families to avoid new placements).

torture whenever a child is placed in an institution.<sup>63</sup> Under the U.N. Convention against Torture (CAT),<sup>64</sup> Méndez stated governments must adopt "legislation, policies, and practices that allow children to remain with family members or guardians in a non-custodial. community-based context."65 To avoid violence and torture, Méndez states that the Convention against Torture requires any placement to be only for "the shortest possible period of time."66 This would limit any long-term placement in residential institutions in any situation in which family-based care could eventually be established. Méndez takes the even stronger position that any detention of immigrant children without their parents "is never in the best interests of the child, exceeds the requirement of necessity, becomes grossly disproportionate and may constitute cruel, inhuman or degrading treatment of migrant children."67

#### A. Pressures on Families to Give Up Their Children

In many societies, poor and marginalized families report that they feel pressure to give up their children because of economic demands and social stigma.<sup>68</sup> It is "widely acknowledged that most parents do not place their children in institutions willingly; rather, they place them out of desperation, believing that they have no choice but to remove their children from their homes and place them in institutions."<sup>69</sup> In much of the world today, parents of children with disabilities are told to place their children in institutions for "necessary treatment and care," and "before they become too emotionally attached" to them.<sup>70</sup> A global study by Inclusion International of people with intellectual

<sup>&</sup>lt;sup>63</sup> Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez ¶ 16, U.N. Doc. A/HRC/28/68 (2015) [hereinafter Méndez 2015 Report].

<sup>&</sup>lt;sup>64</sup> Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Dec. 10, 1984, G.A. Res. 39/46, U.N. Doc. A/RES/29/46 (1987), 1465 U.N.T.S. 85 [hereinafter CAT].

 $<sup>^{65}</sup>$  Méndez 2015 Report, supra note 63, at § 72.

 $<sup>^{66}</sup>$  Id.

 $<sup>^{67}</sup>$  Id. ¶ 80.

<sup>&</sup>lt;sup>68</sup> See generally Rosenthal & Ahern, supra note 61.

<sup>&</sup>lt;sup>69</sup> KANTER, *supra* note 47, at 18.

<sup>&</sup>lt;sup>70</sup> Eric Rosenthal & Laurie Ahern, Segregation of children worldwide: the human rights imperative to end institutionalization, 12 J. PUB. MENTAL HEALTH 193, 196 (2013).

disabilities and their family members found that:

Families throughout these countries tell of parents being advised by professionals to place their child with intellectual disabilities in an institution, forget about them, and get on with their lives; that such a course of action was in the best interest of all concerned. Coupled with a general lack of support for families raising a child with a disability in many countries, the result was a high rate of institutionalization.<sup>71</sup>

More often than not, there is simply no support available to families in the community who face the prospect of financial ruin and social stigma if they try to keep their children at home.<sup>72</sup>

Parents are often improperly blamed for the difficulties of their children, providing authorities "justification" for the improper breakup of families.<sup>73</sup> Mothers with disabilities can have their children taken away from them by child protection systems arbitrarily and without being given any form of social support or treatment.<sup>74</sup> The lack of protections and services for adults with disabilities is a widely overlooked threat to the integrity of the family.<sup>75</sup> The many ways parents are improperly "pathologized" (given a diagnosis of a mental illness or a mental disorder) or blamed for the difficulties of their children results in the avoidable breakup of families.<sup>76</sup> In Romania, a recent UNICEF study found that 21% of children placed in out-of-home care and put up for adoption have parents with disabilities.<sup>77</sup>

 $<sup>^{71}</sup>$  Inclusion International, Inclusive Communities = Stronger Communities 7 (2012).

<sup>&</sup>lt;sup>72</sup> Rosenthal & Ahern, *supra* note 70, at 196.

<sup>&</sup>lt;sup>73</sup> Kumar, *supra* note 60, at 9.

<sup>&</sup>lt;sup>74</sup> DISABILITY RIGHTS INTERNATIONAL, TWICE VIOLATED: ABUSE AND DENIAL OF SEXUAL AND REPRODUCTIVE RIGHTS OF WOMEN WITH PSYCHOSOCIAL DISABILITIES IN MEXICO (2015), *available at* <a href="https://www.driadvocacy.org/wp-content/uploads/">https://www.driadvocacy.org/wp-content/uploads/</a> Mexico-report-English-web.pdf> (visited July 2, 2018).

<sup>&</sup>lt;sup>75</sup> Kumar, *supra* note 60, at 9.

 $<sup>^{76}</sup>$  Id.

<sup>&</sup>lt;sup>77</sup> MANUELA SOFIA STANCULESCU ET AL., UNICEF ET AL., ROMANIA–COPIII DIN SISTEMUL DE PROTECTIVE A COPILULUI, (2016), *available at* <http://www.unicef.ro/wp-content/uploads/Copiii-din-sistemul-de-protectie-a-

A number of factors may contribute to the pressures on parents to give up their children.<sup>78</sup> Deeply ingrained stigma against children with disabilities may bring shame onto an entire family that keeps a child with a disability. When parents are courageous enough to stand up for their disabled child, they may face many forms of discrimination. Since children with disabilities are often excluded from social, cultural, and education programs, parents face tremendous burdens to keep their children. Combined with the lack of government support, keeping a child may mean financial ruin for an entire family. Once children with disabilities are given up by their families, reintegrating them into society is harder than it is for other children. In addition, foster care and adoption programs often exclude children with disabilities.<sup>79</sup>

## **B.** International Support for Outmoded Government Policies

Despite international policies strong against institutions, there are many pressures on families leading to new placement of children. The forces that lead to the breakup of families have, unfortunately, received support from misguided development and donor practices that support the institutionalization of children. In many parts of the world, extensive charity aid and volunteer support creates incentives for governments or private business to build new orphanages.<sup>80</sup> International assistance programs often have an impact far beyond the cash value of assistance. The plaque on the wall of the institution from a prestigious donor signals that a program is respected by the international

copilului\_UNICEF\_ANPDCA\_BM\_2016.pdf> (Romania-Children in the child protection system).

<sup>&</sup>lt;sup>78</sup> Rosenthal & Ahern, *supra* note 70, at 46. Disability Rights International (DRI) has documented this problem in numerous countries. See reports from Argentina, Hungary, Mexico, Peru, Republic of Georgia, Romania, Serbia, Turkey, Ukraine, the United States, Uruguay, and Vietnam, available at <www.DRIadvocacy.org>.

<sup>&</sup>lt;sup>79</sup> Cantwell, *supra* note 21, at 267.

<sup>&</sup>lt;sup>80</sup> See Rosenthal & Ahern, *supra* note 70, at 193-200 (describing the global pressures leading to institutionalization); *see also* Jacob Kushner, *The Voluntourists's Dilemma*, N.Y. TIMES, Mar. 22, 2016 (describing the role of international volunteers in supporting orphanages); Cantwell, *supra* note 21, at 269.

community.<sup>81</sup> High-profile volunteers in a program may have the same impact.

Governments may invest in institutions or group homes under the misguided assumption that these services are less expensive than community-based services and supports. Governments face financial, cultural, and legal barriers to introducing new models of family support in parts of the world that have a long tradition of placing children in institutions.<sup>82</sup> There are particularly significant challenges for family placement of children with disabilities in countries that have no history of disability inclusion.

In the long term, however, family and community placement are usually more cost-effective than residential care or institutions.<sup>83</sup> These findings also hold true when group homes are compared to foster care: group homes prove to be more costly and have worse outcomes.<sup>84</sup>

Developing countries may lack trained professionals and have many competing demands for government funding; however, the most progressive solutions for full family and community inclusion do not rely on heavily funded programs or highly trained professions. The best practices for inclusion build on what are called "natural supports" that are already in the community: family, friends, and existing social

 $<sup>^{81}</sup>$  See, e.g., DISABILITY RIGHTS INTERNATIONAL, THE EXCLUSION OF CHILDREN AND ADULTS WITH DISABILITIES FROM REFORM AND RIGHTS PROTECTION IN THE REPUBLIC OF GEORGIA (2013), *available at* <a href="https://www.driadvocacy.org/wp-content/uploads/Left-Behind-final-report1.pdf">https://www.driadvocacy.org/wpcontent/uploads/Left-Behind-final-report1.pdf</a> (visited Apr. 25, 2018). The implications of U.S. government funding in Georgia are further described in Part V *infra*.

 $<sup>^{82}</sup>$  Cantwell, supra note 21, at 267.

<sup>&</sup>lt;sup>83</sup> See Richard Carter, *supra* note 52, at 2 ("Every Child's assessment of the evidence indicates that on average, institutional care is twice as the most costly alternative: community residential/small group homes; three to five times as expensive as foster care (depending on whether it is provided professionally or voluntarily); and around eight times more expensive than providing social services-type support to vulnerable families"); SAVE THE CHILDREN, THE RISK OF HARM TO YOUNG CHILDREN IN INSTITUTIONAL CARE 6 (2009) ("Analyses of children of all agencies in Romania, Ukraine, Moldova, and Russia show that institutional care is six times more expensive than providing social services to vulnerable families or voluntary kinship carers [and] three times for expensive than professional foster care").

<sup>&</sup>lt;sup>84</sup> Allen D. DeSelena et al., *SAFE HOMES: Is it worth the cost? An evaluation* of a group home permanency planning program for children who first enter outof-home care, 29 CHILD ABUSE & NEGLECT 627-643 (2005). Part IV of this article describes the CRPD framework for protecting this right.

networks.<sup>85</sup>

Nonetheless, international donors have perpetuated the segregation of children by promoting a transition to smaller institutions.<sup>86</sup> Where international development organizations and governments have offered funding and technical assistance, large, older orphanages have often been replaced by smaller "family-like" institutions and group homes.<sup>87</sup> In many cases, the creation of group homes has become "the default solution that presumes to embody the principles of the right to live in the community."<sup>88</sup>

<sup>88</sup> RIGHT TO LIVE INDEPENDENTLY, *supra* note 35, at 27. Some countries that have been identified as the greatest success stories in the closure of institutions and the integration of children into the community have largely moved children out of orphanages and into a new system of group homes. Bulgaria, for example, has been lauded for making "significant progress in deinstitutionalization (the process of removing children from institutional care and moving toward familybased care) in a short space of time: the number of children in institutions has decreased by 78% since 2009." LUMOS, ENDING INSTITUTIONALIZATION: AN ASSESSMENT OF THE OUTCOMES FOR CHILDREN AND YOUNG PEOPLE IN BULGARIA WHO MOVED FROM INSTITUTIONS TO THE COMMUNITY 4 (2018). A closer examination of the outcomes shows that the majority of "community" placement was actually

<sup>&</sup>lt;sup>85</sup> Rosenau, *supra* note 58; Alicia DeLashmutt, *Homes, Not Housing*, 41 TASH CONNECTIONS 3 (Fall 2015), *available at* <a href="https://tash.org/wp-content/uploads/2016/05/Connections-v41n3-DeLashmutt.pdf">https://tash.org/wp-content/uploads/2016/05/Connections-v41n3-DeLashmutt.pdf</a>.

<sup>&</sup>lt;sup>86</sup> A coalition of disability groups have sent documentation to European authorities about the use of EU funds to build smaller institutions. *See* European Network on Independent Living, the European Disability Forum, Validity, and Disability Rights International (DRI), Letter to Marianne Thyssen, Commissioner for Employment, Social Affairs, Skills and Labour Mobility, European Union, Jan. 14, 2019 (on file with author). *See* European Network on Independent Living, *Briefing on the Use of EU Funds for Independent Living* (March 2018), *available at* <a href="https://enil.eu/wp-content/uploads/2018/04/EU-Funds-Briefing\_web0903.pdf">https://enil.eu/wp-content/uploads/2018/04/EU-Funds-Briefing\_web0903.pdf</a>> (report with documentation on the use of funds for smaller institutions and group homes).

<sup>&</sup>lt;sup>87</sup> Romania is the country best known for its history of confining thousands of children to large and abusive institutions. As a condition for the country's accession to the European Union, Romania was called on to reduce its institutional population. Romania has made great process in closing down many of the large institutions of the past, but according to official government statistics there remain more than 7,000 children still in institutions in the country. At the same time, there has been a parallel system of smaller institutions, residential facilities and group homes created with international assistance. According to official statistics, there are more than 7,000 children residing in this parallel system of residential services. *See* National Authority for the Protection of the Rights of the Child and Adoption, *Statistical Bulletin on Labor and Social Protection in Quarter III of 2017*, at 7 (in Romanian), available at <http://www.mmuncii.ro/j33/images/buletin\_statistic/copil\_trim\_III-\_2017-1.pdf> (visited April 12, 2018).

the prominent Some of most international organizations committed to ending or reducing placement of children in orphanages defend the practice of placement of some children in group homes by relying primarily on the argument that they are necessary as a last resort.<sup>89</sup> Once such arguments are used (that there is no other choice because of inadequate social service systems), there is no need to make a more detailed argument, based on reference to scientific evidence, that such placement is in the best interest of the child. One of the best policy papers on the dangers of orphanages by the Better Care Network, a highly respected policy advocacy organization, defends the use of group homes "in some countries and in some specific cases" for 8 to 10 children as long as placement is "regularly reviewed with the aim of placing that child back into family care."90 This paper is a carefully written report based on extensive citations to research literature on the dangers of institutions and residential care. It is striking, therefore, that the paper allows for group home placement without citing any scientific evidence that the benefits outweigh the dangers of group home for any particular child. It never explains why the 8 to 10 beds are acceptable and larger or smaller group homes are not-nor does it warn of the

<sup>89</sup> One such organization states that residential care should be used when it "is the best currently available alternative to an abusive family situation, and it can be a short-term measure until the child can be placed with a family." LUMOS, ENDING INSTITUTIONALIZATION, *supra* note 88, at 3. The authors also suggest that adolescents be allowed to voluntarily choose group home placement. The issue of choice and consent is addressed in Part V-D *infra*.

<sup>90</sup> JOHN WILLIAMSON & AARON GREENBERG, FAMILIES NOT ORPHANAGES: A BETTER CARE NETWORK WORKING PAPER 4 (2010). It is also notable that the size of the group homes in this paper are never justified. Even for adults, 8-10 bed group homes result in lower quality of life than smaller homes. *See* JAMES CONROY, CENTER FOR OUTCOME ANALYSIS, SIZE, QUALITY, AND COST OF RESIDENTIAL SETTINGS: POLICY ANALYSIS OF LITERATURE AND LARGE DATA SETS 3-4 (2010), *available at* <a href="http://www.eoutcome.org/Uploads/COAUploads/">http://www.eoutcome.org/Uploads/COAUploads/</a> PdfUpload/ SizeReportConroy2011-V64Final.pdf> (showing through a longitudinal outcome study that, for adults, indicators of quality of life are reduced rapidly in homes larger than six beds).

placement in group homes and not in family. From 2010 to 2015, 2,115 children were "transitioned out of institutions to new placements." Of these children, 1,291 were moved from institutions to group homes, 105 were moved to other institutions, including homes for the elderly, 150 children died, and 87 were moved to services "outside the project." Only a small number were able to live with a family: 327 were adopted, 77 were placed in foster family, and 78 were re-integrated with their original family. *Id.* at 14-15.

conditions or circumstances of a child that might make placement in a group home particularly dangerous or inappropriate (above and beyond those experienced by other children). While the authors of this study clearly intend to support family rather than group home placement, a blanket statement justifying group homes when no other options are available can open the floodgates: it allows for group home placement as if it is a one-size-fits-all solution to inadequate social care systems where the child must fit in with whatever services that happen to be made available.

There are still other organizations that justify the use of group homes based on disability and suggest that this is the best outcome for particular children. One international organization dedicated to ending global orphanage placement states that group homes are needed for children "who have already experienced multiple placement breakdowns, those with extreme behavioral concerns, or children with complex disabilities."<sup>91</sup> As described in Part II, experience has shown that all children with disabilities can be supported to live with families.<sup>92</sup> Even though implementation of this goal is a challenge, advocates and professional groups have endorsed the goal of full inclusion of *all* children in families.<sup>93</sup>

<sup>&</sup>lt;sup>91</sup> LUMOS, DOLLARS AND SENSE: SUPPORTING CHILDREN OUTSIDE OF FAMILY CARE: OPPORTUNITIES FOR U.S. GOVERNMENT INTERNATIONAL ASSISTANCE 4 (2018). In describing the "Lumos approach" to transforming institutional care, a "very small number need some form of high-quality residential care. This care can be provided in small units with 4-6 children in each, integrated into the community (a regular house on a regular street), and with highly trained personnel in number." Georgette Mulheir & Lynn Lina Gyllensten, sufficient Institutionalization and the commodification of children: How to ensure children regain their right to family life, in ROUTLEDGE HANDBOOK OF GLOBAL CHILD WELFARE 305 (Pat Dolan & Nick Frost eds., 2017). Even in the description of this model of services, however, there is no effort to draw on research that would demonstrate that some children need such group care. And while the children supposed to be placed in group homes under the Lumos model is very limited, in practice a much larger group of children has been placed in group homes in some countries where the Lumos model has been implemented, such as Bulgaria. See discussion in note 88 supra.

 $<sup>^{92}</sup>$  See discussion in text accompanying notes 142-43 infra.

<sup>&</sup>lt;sup>93</sup> See, e.g., TASH, Resolution on Life in the Community (July 2000), available at https://tash.org/about/resolutions/tash-resolution-life-community/ (visited June 13, 2018) ("THEREFORE BE IT RESOLVED, THAT TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field, believes that all children, regardless of disability, belong with families and need enduring

The challenge of effective community and family inclusion is ultimately one of implementation. Charities working in developing countries without foster care or community supports for families rightly feel the urgency to move quickly to close down large, old orphanages, and replacing them with smaller, newer residences may seem like a great improvement. But the danger of using group homes as a temporary step until better services are created is that such programs are likely to become permanent. The reform of one moment becomes the source of new human rights abuses thereafter. The prestigious names of international donors placed on the walls of the new buildings send a message to governments and other reformers that this is the new internationally-accepted model of care. And if group homes are reserved for children with "complex disabilities" and serious "behavioral concerns," the children placed in these facilities become so labeled. As described below, there is extensive data showing that governments and international donors can do better.

# II. LESSONS FROM RESEARCH AND PRACTICE

The evolution of protections for children to live and grow up in a family under the CRPD is consistent with new understandings and lessons learned from research and practice. Concerns about the dangers of raising children in institutions go back decades. Recognizing the importance of the family, the United States has had policies against placing children in orphanages since the White House Conference on the Care of Dependent Children in 1909.<sup>94</sup> But in recent years there has been an "exponential growth" of findings from research about the need for *all* children—with and without disabilities—to grow up in families.<sup>95</sup> The

<sup>95</sup> See Better Care Network, GLOBAL FACTS ABOUT ORPHANAGES 6-7 (2009) (summarizing extensive research on the psychological dangers of orphanages).

relationships with adults. The actions of states and agencies involved with children should be guided by the philosophy of permanency planning. As a guide to state and agency practice, permanency planning requires the funding of family support services, encouragement of a family's relationship with their child, family reunification of children placed out of home, and the pursuit of adoption when family reunification or some form of shared care is not possible.") (emphasis added). *See* discussion in text accompanying note 124 *infra*.

<sup>&</sup>lt;sup>94</sup> ANDREW L. YARROW, FIRST FOCUS, HISTORY OF U.S. CHILDREN'S POLICY 1900-PRESENT 2 (2009), *available at* <a href="https://firstfocus.org/wp-content/uploads/2014/06/Childrens-Policy-History.pdf">https://firstfocus.org/wp-content/uploads/2014/06/Childrens-Policy-History.pdf</a>> (visited May 15, 2018).

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development of service systems in areas where all institutions have closed has demonstrated that deinstitutionalization is possible, even for children with the most severe disabilities and with the most serious behavioral issues.<sup>96</sup>

## A. Dangers of Institutions and Group Care

It should no longer be possible to say that it is in the best interest of any child to be placed in a "suitable institution."<sup>97</sup> There is now a universal consensus that children are better off growing up with families rather than in institutions:

> It would be difficult to identify any current evidence-based study that takes issue with the finding that, not only do placements in institutional care generally have less favorable outcomes than those in family-based settings, but also that those placements often have a children's negative impact on overall development that may be serious and irreversible.98

The modern consensus that all children, with and without disabilities, need to grow up in a family has grown over decades of research.<sup>99</sup> Placement of young children in institutions has been shown to be associated with abnormal brain development, increasing risks for emotional, cognitive,

<sup>&</sup>lt;sup>96</sup> Raymond Lemay, Deinstitutionalization of People with Developmental Disabilities: A Review of the Literature, 28 CANADIAN J. COMMUNITY MENTAL HEALTH 181-94 (2009).

<sup>&</sup>lt;sup>97</sup> See, e.g., InBrief: The Science of Neglect (YouTube video of the Harvard Center on the Developing Child, Oct. 31, 2013), available at <https://www.youtube.com/watch?v=bF3j5UVCSCA>; NATIONAL SCIENTIFIC COUNCIL ON THE DEVELOPING CHILD, THE SCIENCE OF NEGLECT: THE PERSISTENT ABSENCE OF RESPONSIVE CARE DISRUPTS THE DEVELOPING BRIAN: WORKING PAPER 12 (2012), available at <https://developingchild.harvard.edu/resources/the-science-of-neglect-the-persistent-absence-of-responsive-care-disrupts-the-

developing-brain/> (visited June 18, 2018) [hereinafter THE SCIENCE OF NEGLECT].

<sup>&</sup>lt;sup>98</sup> Nigel Cantwell, *supra* note 21, at 268.

<sup>&</sup>lt;sup>99</sup> *Id.* While there are common misconceptions that some children with disabilities need treatment in some form or residential facility, awareness about the universal need for a family goes back decades. *See* JOSEPH GOLDSTEIN, ET AL., BEYOND THE BEST INTEREST OF THE CHILD (1973).

and behavioral disorders.<sup>100</sup> Research has shown that in their first years, children learn to form emotional attachments with caregivers, and they may lose this ability if they do not have stable family members in their lives with whom they can form emotional attachments.<sup>101</sup>

While the emphasis of research on attachment focused on the child's earliest years of development, children at any age fall further behind in their intellectual and cognitive development the longer they are in a group setting.<sup>102</sup> Longitudinal studies have shown that institutional care has profoundly damaging effects across multiple domains of development. One such study, the Bucharest Early Intervention Project, has compared the outcomes of children in institutions with other children randomly assigned to foster care.<sup>103</sup> This study shows that children moved from institutions to foster care showed significant improvement in physical growth, language and intellectual functioning, indices of stress reactivity, assessments of emotional and behavioral adaptation, and measures of brain development.<sup>104</sup>

There are limited scientific studies that have tried to show rates of abuse among institutionalized children, but the ones that have produced results have produced shocking conclusions. A study in Tanzania found that 89% of children reported "at least one experience of abuse, more so among those institutionalized at birth."<sup>105</sup> One large study among boys and girls from institutions in five African countries found that more than 50% of children reported experiences of physical or sexual abuse.<sup>106</sup> A study of adolescents institutionalized in the Netherlands found that 31% of boys and 18% of girls reported physical abuse.<sup>107</sup> A large study of

<sup>105</sup> Lorraine Sherr et al., *Child Violence Eexperiences in Institutionalized/Orphanage Care*, 22 PSYCHOL. HEALTH & MED. 31, 40 (2017).

<sup>&</sup>lt;sup>100</sup> The Science of Neglect, *supra* note 97, at 5.

<sup>&</sup>lt;sup>101</sup> *Id.* at 7.

<sup>&</sup>lt;sup>102</sup> WILLIAMSON & GREENBERG, *supra* note 90, at 6.

<sup>&</sup>lt;sup>103</sup> See Charles H. Zeanah, et al., Alternatives for Abandoned Children: Insights from the Bucharest Early Intervention Project, 15 CURR. OPIN. IN PSYCHOL. 182, 182 (2017).

<sup>&</sup>lt;sup>104</sup> A.T. Smyke et al., *Placement in Foster Care Enhances Quality of Attachment Among Young Institutionalized Children*, 81 CHILD DEV. 212, 217-21 (2010), *available at* <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1467-8624.2009.01390.x>">https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1467-8624.2009.01390.x></a>.

 $<sup>^{106}</sup>$  Id.  $^{107}$  Id.

more than 1,300 children in Romanian institutions found that 39.5% reported severe punishment and beatings by staff. Among these children, 80% reported that abuses occurred many times.<sup>108</sup>

In addition to a focus on psychology and development, studies now show that children of all ages raised in institutions are at a heightened risk of violence, sexual abuse, forced labor, and sex trafficking.<sup>109</sup> Some studies have found that girls are more likely to be victims of sexual exploitation or trafficking<sup>110</sup> if they were raised in institutions rather than in families.<sup>111</sup> In many countries, forced labor within orphanages is widespread and institutions are "feeders" for human trafficking.<sup>112</sup> Citing findings from around the world, the U.S. Department of State's Trafficking in Persons Report in 2018 described how placement of children in orphanages contributes to their vulnerability to exploitation and trafficking:

> Children in institutional care, including government-run facilities, can be easy targets for traffickers. Even at their best, residential institutions are unable to meet a child's need for emotional support that is typically received from family members or consistent caretakers with whom the child can develop an attachment. Children are especially vulnerable

FIRE: SURVIVORS OF HOGAR SEGURO VIRGEN DE LA ASUNCIÓN AT RISK (2017), available at <https://www.driadvocacy.org/wp-content/uploads/After-the-Fire-March-15.pdf> (visited Apr. 10, 2018). See also Georgette Mulheir, Deinstitutionalization: A Human Rights Priority for Children with Disabilities, 9 EQUAL RTS. REV. 120 (2012).

<sup>111</sup> U.S. DEPARTMENT OF STATE, *supra* note 3, at 22.

<sup>112</sup> Laurie Ahern, Orphanages are no place for children, WASH. POST, Aug. 9, 2013; Laurie Ahern, Ukraine Orphanages Feeder for Child Trafficking, HUFF. POST, June 2, 2016; Laurie Ahern, Donors Need to Support Vulnerable Families Not Rebuild Nepalese Orphanages, HUFF. POST, May 22, 2016.

 $<sup>^{108}</sup>$  Id.

<sup>&</sup>lt;sup>109</sup> Dozier et al., *supra* note 43, at 222.

<sup>&</sup>lt;sup>110</sup> DISABILITY RIGHTS INTERNATIONAL, NO JUSTICE: TORTURE, TRAFFICKING SEGREGATION MEXICO (2015),available AND IN at<https:// www.driadvocacy.org/wp-content/uploads/Sin-Justicia-MexRep 21 Abr english-1.pdf> (visited Apr. 10, 2018); DISABILITY RIGHTS INTERNATIONAL, TWICE VIOLATED ABUSE AND DENIAL OF SEXUAL AND REPRODUCTIVE RIGHTS OF WOMEN WITH PSYCHOSOCIAL DISABILITIES IN MEXICO (2015). available at<https://www.driadvocacy.org/wp-content/uploads/Mexico-report-Englishweb.pdf> (visited Apr. 10, 2018); DISABILITY RIGHTS INTERNATIONAL, AFTER THE

when traffickers recognize and take advantage of this need for emotional bonding stemming from the absence of stable parental figures. In addition, the rigid schedules and social isolation of residential institutions offer traffickers a tactical advantage, as they can coerce children to leave and find ways to exploit them.<sup>113</sup>

Disability Rights International (DRI), the organization I lead, has conducted human rights investigations in orphanages and institutions in more than two dozen countries over twenty-five years and documented the widespread and severe human rights violations that take place whenever children are separated from families.<sup>114</sup> DRI's findings demonstrate the link between violence, abuse, and exploitation of children—and how they are fueled by international funding for institutions large and small. This link is tragically demonstrated by the case of Hogar Seguro Virgen de la Asuncion, an orphanage in Guatemala where forty-one girls burned to death in March 2017. The girls who died at the facility had been rioting to protest being raped and forced into prostitution by Hogar Seguro staff. They were silenced by being locked in a storage room, and it took more than forty minutes for them to be rescued after the fire started. After the disaster hit the international press, there were international calls for the reform of Guatemala's orphanage system.<sup>115</sup> There are more than one hundred internationally-funded orphanages in Guatemala, but there are only thirty foster placements in the entire country.<sup>116</sup> Hundreds of children who lived in the institution before the fire are still not accounted for and may have been trafficked again. The government has since built large and small "group homes," where these children languish. Without any forms of support to help children with disabilities return to families, many of these children were placed in other abusive facilities. Many of them remain in barren rooms with shaved

<sup>&</sup>lt;sup>113</sup> U.S. DEPARTMENT OF STATE, *supra* note 3, at 22.

 $<sup>^{114}</sup>$  Rosenthal & Ahern, supra note 70, at 193-200 (summarizing DRI's findings from around the world).

<sup>&</sup>lt;sup>115</sup> Eric Rosenthal, *The Guatemala Fire Tragedy Shows Why it's Time to Get Rid of Orphanages*, WASH. POST (Mar. 22, 2018), *available at* <https://www.washingtonpost.com/news/global-opinions/wp/2017/03/22/theguatemala-fire-tragedy-shows-why-its-time-to-get-rid-of-orphanages/? noredirect=on&utm\_term=.16d677268c21> (visited Apr. 27, 2018).

<sup>&</sup>lt;sup>116</sup> DISABILITY RIGHTS INTERNATIONAL, AFTER THE FIRE, *supra* note 110.

heads, tied to wheelchairs.<sup>117</sup>

These findings are consistent with what DRI has observed in dozens of other countries around the world.<sup>118</sup> DRI has documented abuses in the institutions of every country we have visited. In Argentina, Peru, Uruguay, Hungary, Serbia Romania, Ukraine, Turkey, Mexico, Guatemala and Kenya, DRI found children tied to beds, locked in cages, or placed in isolation cells. Children detained in adult facilities and psychiatric hospitals are particularly at risk. In Romania, after the government promised it would reduce the number of children in orphanages in 2006, DRI found children abandoned in cribs in adult psychiatric facilities. Their arms and legs were atrophied and children were emaciated despite being offered food. Left in a position of neglect, they suffered from a failure to thrive. At the Federico Mora psychiatric facility in Guatemala, DRI investigators asked why a 15 year old boy was kept in a locked isolation cell. Staff reported that this was the only way to keep the boy from being raped; he could not be mixed in with the general population of adult detainees and armed guards. DRI also received reports that the armed guards took payments from outsiders to have sex with detainees.

Children with disabilities are often subject to atrocious abuses based on the perception that they feel no pain. In Turkey, orphanage authorities reported removing children's teeth with pliers and no anesthetic.<sup>119</sup> At the Bakirkoy psychiatric facility in Istanbul, thousands of children and adults were subjected to electro-convulsive treatment (ECT) without anesthesia (this practice was reportedly stopped after the release of DRI's report in 2006).<sup>120</sup>

In the Republic of Georgia (profiled further in Part IV), children with hydrocephalus were left to die without

<sup>&</sup>lt;sup>117</sup> DISABILITY RIGHTS INTERNATIONAL, STILL IN HARM'S WAY: VOLUNTOURISM, VIOLENCE, AND CONFINEMENT OF CHILDREN IN GUATEMALA (2018), *available at* <https://www.driadvocacy.org/wp-content/uploads/Still-in-Harms-Way-2018.pdf> (visited Dec. 12, 2018).

<sup>&</sup>lt;sup>118</sup> All findings described in this paragraph are documented in respective country reports posted on the DRI website at www.DRIadvocacy.org.

<sup>&</sup>lt;sup>119</sup> MENTAL DISABILITY RIGHTS INTERNATIONAL, BEHIND CLOSED DOORS: HUMAN RIGHTS ABUSES IN THE PSYCHIATRIC FACILITIES, ORPHANAGES AND REHABILITATION CENTERS OF TURKEY 23 (2005), *available at* <https://www.driadvocacy.org/wp-content/uploads/Sin-Justicia-MexRep\_21\_ Abr\_english-1.pdf> (visited Apr. 10, 2018).

 $<sup>^{120}</sup>$  Id.

medical treatment that was readily available in the country because the children were considered "already damaged" due to disability.<sup>121</sup> At the time of DRI's visits in 2011, the Tbilisi Infants Home had a 30% annual mortality rate.<sup>122</sup> DRI brought in a medical expert who found that these children's deaths could have been avoided entirely—but they were left to die in extreme pain as their heads filled with fluid.<sup>123</sup>

# B. Dangers of Group Homes and "Family-Like" Residences

An extensive body of research and experience has shown that *all* children need a safe and nurturing environment where they can establish long-term permanent emotional bonds with their caregivers. While the youngest children are especially at risk, this need is not limited to young children. "Children of *all ages* need long-term, supportive parenting relationships – permanence, in child welfare parlance."<sup>124</sup> As stated by TASH, one of the leading international organizations of people with disabilities, families, and developmental disability professionals, "all children, regardless of disability, belong with families and need enduring relationships with adults."<sup>125</sup> The American Academy of Pediatrics endorsed the U.S. government's Healthy People 2010 program to "reduce to zero the number

<sup>&</sup>lt;sup>121</sup> DISABILITY RIGHTS INTERNATIONAL, LEFT BEHIND: THE EXCLUSION OF CHILDREN AND ADULTS WITH DISABILITIES FROM REFORM AND RIGHTS PROTECTION IN THE REPUBLIC OF GEORGIA (2013), *available at* <a href="https://www.driadvocacy.org">https://www.driadvocacy.org</a> /media-gallery/our-reports-publications/>.

 $<sup>^{122}</sup>$  Id.

 $<sup>^{123}</sup>$  Id.

<sup>&</sup>lt;sup>124</sup> ANNIE E. CASEY FOUNDATION, RECONNECTING CHILD DEVELOPMENT AND CHILD WELFARE: EVOLVING PERSPECTIVES ON RESIDENTIAL PLACEMENT 3 (2013) (summarizing the findings of an international team of experts convened by the Annie E. Casey Foundation and the Youth Law Center) (emphasis added). One important review of children in out-of-home care compared children who attained permanence in a family setting to those who did not. Permanence was associated with decreased risk of incarceration; food, housing, and income insecurity; unemployment, educational deficits; receipt of public assistance, and persistent mental health disorders. *See* Katie K. Lockwood et al., *Permanency and the Foster Care System*, 45 CURR. PROBS IN ADOLESCENT HEALTH CARE 306, 309 (2015); see also Arlene Kanter, *Permanency Planning for Children with Disabilities: The Right to Live with a Family for Every Child*, 28 CHILD LEGAL RTS. J. 1 (2008) (describing legal and policy options to promote permanency in families).

<sup>&</sup>lt;sup>125</sup> TASH, *supra* note 93.

of children aged 17 and younger living in congregate care facilities."  $^{126}$ 

Research now demonstrates that the dangers of an institution will be created in *any* environment that is not a family. Based on a review of current research, a consensus statement of the American Orthopsychiatric Association concludes that "group settings should not be used as living arrangements, because of their *inherently detrimental* effects on the healthy development of children, regardless of age."<sup>127</sup>

Group homes and "family-like" residences are not a substitute for families for a broad array of reasons. The most basic limitation of any residential program other than a family or foster family is that the staff works in shifts and it is impossible for children to establish the permanent attachments with adults that they need for their emotional growth and well-being.<sup>128</sup> Children with and without disabilities thrive on inclusion in families that are as close to a mainstream environment as possible.

Families and family-based care are imperfect, but on the whole they are better than the alternatives. Any type of care, family-based or residential, can be implemented badly and damage children. It is clear, though, that the available literature on child development indicates that families have better potential to enable children to establish attachments and offer opportunities for individual development and social connectedness than any form of group residential care.<sup>129</sup>

Whether or not they are labeled with a disability, children transferred to group homes from institutions are likely to have experienced multiple forms of trauma.<sup>130</sup> These

<sup>&</sup>lt;sup>126</sup> AMERICAN ACADEMY OF PEDIATRICS, OUT-OF HOME PLACEMENT FOR CHILDREN AND ADOLESCENTS WITH DISABILITIES 836, 837 (2014). Recognizing the challenges to implementation of this goal, the American Academy of Pediatrics (AAP) later endorsed the "more realistic" program of Healthy People 2020 to "reduce the number of children and youth aged 21 years and under with disabilities living in congregate care residences" by 10% by 2019. *Id.* at 837. In doing so, the Council on Children with Disabilities of the AAP did not endorse eliminating all congregate care recognizing its need for medical treatment that could not be provided in the home. *Id.* 

<sup>&</sup>lt;sup>127</sup> Dozier et al., *supra* note 43, at 219 (emphasis added).

 $<sup>^{\</sup>rm 128}$  Id. at 220.

<sup>&</sup>lt;sup>129</sup> WILLIAMSON & GREENBERG, *supra* note 90, at 20.

<sup>&</sup>lt;sup>130</sup> Given the high rates of violence and abuse in institutions, cited in Part II.A *supra*, it can be assumed that all children once placed in institutions have been subject to trauma. More broadly, in the United States, children placed in the child welfare system are "almost universally from a place of trauma or neglect." Katie K. Lockwood, *supra* note 124, at 312. Studies from the United

children may have faced violence in the family or they may have been subject to abuse because they have lived without the protection of a family. Most children will experience trauma from the emotional impact of family separation itself.<sup>131</sup> Grouping children into homes with peers who are experiencing similar emotional difficulties is likely to create "iatrogenic effects,"<sup>132</sup> where the emotional difficulties of one child become even worse as a result of exposure to other children experiencing emotional challenges. A review of the research literature by the Casey Foundation found that:

The vast majority of research pointed in the same direction. Residential care lacks sufficient parent-like adult relations to be appropriate long-term placement for maltreated children; these facilities mirror too closely aspects of maltreatment that set children up for life-long development challenges.<sup>133</sup>

Unlike with adults, the dangers for children of placement in a group home are not limited based on the small size of the facility. Studies from Romania show that even children "placed in small family-like homes with four consistent caregivers" experienced serious attachment problems.<sup>134</sup>

The need of young children to grow up with a family has been well documented and is now widely understood.<sup>135</sup> But research shows that family placement is also critical for older children and adolescents.<sup>136</sup> Some experts believe that group settings may be appropriate for very short-term treatment of adolescents.<sup>137</sup> Even for children and adolescents with mental health needs, however, the research shows that there is "no demonstrable therapeutic necessity for group care to be used as a long-term living arrangement."<sup>138</sup> Research on the dangers of group homes

States also show that 70% of children who enter foster care have experienced maltreatment. *See* DeSelena, *supra* note 84 (reviewing findings from a sample of 345 children placed in group homes in Connecticut).

<sup>&</sup>lt;sup>131</sup> Dozier et al., *supra* note 43, at 221.

<sup>&</sup>lt;sup>132</sup> Id. at 220.

<sup>&</sup>lt;sup>133</sup> ANNIE E. CASEY FOUNDATION, *supra* note 124, at 7.

 $<sup>^{134}</sup>$  Save the Children, *supra* note 51, at 13.

<sup>&</sup>lt;sup>135</sup> Dozier et al., *supra* note 43, at 223.

<sup>&</sup>lt;sup>136</sup> *Id.* at 222.

<sup>&</sup>lt;sup>137</sup> ANNIE E. CASEY FOUNDATION, *supra* note 124.

<sup>&</sup>lt;sup>138</sup> Dozier et al., *supra* note 43, at 222.

does not necessarily apply to crisis treatment or respite care, where short-term group care for adolescents may be justified.<sup>139</sup> The implications of these findings are that improving staffing or quality of care within group homes cannot make them appropriate for the long-term care of children.<sup>140</sup> Group care might be used for temporary treatment or respite, but the term "group home"—suggesting permanence of such placement—cannot be justified.

Some disability experts take an even stronger stand, questioning whether short-term group care as treatment can be justified. They are critical of providers of group homes who have made the argument that some children with severe behavioral problems or multiple disabilities can *never* be placed with a family.<sup>141</sup> One top expert responds as follows:

> The impression, sometimes stated outright and sometimes merely implied by our practices, is that some kids are 'just not family material.' This myth is best dispelled by the fact that a child with every kind and severity of impairment is currently living successfully with a family . . . . The impairment alone is not the reason for non-family life. We must look beyond the child for an explanation. A more complex understanding leads to consideration of two areas (1) the nature of supports to families and (2) the recruitment of alternate families... Clearly, a commitment to families as a priority requires a commitment to funding and designing supports that will provide whatever it takes to make that possible. Importantly, whatever it takes does not mean whatever it costs, but equally important it does not mean whatever is available.<sup>142</sup>

Models of care have been established showing that children with the most serious behavioral issues and multiple

<sup>&</sup>lt;sup>139</sup> *Id.* at 221.

<sup>&</sup>lt;sup>140</sup> The Casey conference concluded that "the question is not how to make residential or group settings more like family homes but to be rigorous in ensuring that these residential facilities are used only in the narrow circumstances in which their services have proven to be effective." ANNIE E. CASEY FOUNDATION, *supra* note 124, at 8.

<sup>&</sup>lt;sup>141</sup> LUMOS, *supra* note 91, at 4.

<sup>&</sup>lt;sup>142</sup> Rosenau, *supra* note 58, at 7.

disabilities can be supported to live with families.<sup>143</sup>

Thus, the limitation on family placement of children is *not* because of the disability of the child but because of the lack of resources and support systems for families. The obligation of governments to provide such funding has now come to be understood as a requirement of international law to protect them from discrimination and torture – including the damage that occurs when children are separated from family and community.<sup>144</sup>

The consensus that group homes are bad for children is part of a broader trend in understanding the best way to serve people with disabilities. This is part of a larger shift away from what may be called a "services or continuum of care paradigm" to a "support paradigm."<sup>145</sup> Instead of a "continuum of care" in which institutions, treatment centers, or group homes are bundled together, the support paradigm builds on what are called "natural supports" in the context of families and extended families. The need for this shift is especially true for children who—no matter their level of disability—have a common need and ability to grow up in a family.<sup>146</sup> As one expert observed, "[w]hile treatment can occur in a family, family cannot occur in a facility."<sup>147</sup>

Group homes were once considered a safe and appropriate alternative to institutions for children as well as adults.<sup>148</sup> For adults, freedom, autonomy, and choice are key factors contributing to quality of life, and so these are key factors in determining what an institution is for an adult.<sup>149</sup> Placement of adolescents and adults is still widely accepted, but research has shown that such homes may deny

<sup>&</sup>lt;sup>143</sup> John C. Berens & Cynthia Peakock, Implementation of an academic adult primary care clinic for adolescents and young adults with complex, chronic childhood conditions, 8 J. PEDIATRIC REHABILITATION MED. 3-12 (2015); Patrick H. Casey et al., Home Visiting and Health of Preterm Infants, 56 CLINICAL PEDIATRICS 828 (2017).

 $<sup>^{144}</sup>$  The duty of governments to implement the right to a family is described in Part III-C *infra* of this article.

<sup>&</sup>lt;sup>145</sup> Rosenau, *supra* note 58, at 3.

 $<sup>^{146}</sup>$  Id. at 7.

<sup>&</sup>lt;sup>147</sup> *Id.* at 4.

<sup>&</sup>lt;sup>148</sup> Arlene Kanter, A Home of One's Own, The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Disabilities, 43 AM. U. L. REV. 925, 932 (1994) (discussing the right to community integration and the evolving understanding of the "meaning of a home").

<sup>&</sup>lt;sup>149</sup> KANTER, *supra* note 47, at 19-29. *See also* General Comment No. 5, *supra* note 36, ¶ 16(a) (examining factors relating to the definition of an institution for an adult).

individuals choice and control over their lives and may reproduce the same dangers that exist in institutions for people of any age. For these reasons, disability activists in the United States have long struggled against group home placement as the sole option for community integration.<sup>150</sup> Inclusion International has also raised concerns about this trend. In a worldwide study of the experiences of people with intellectual disabilities in 2012, Inclusion International found that around the world, group homes were often the only choice offered to them other than the institution.<sup>151</sup> In Europe, after the adoption of the CRPD, disability experts warned of the dangers of group homes becoming the main focus of reform and deinstitutionalization efforts.<sup>152</sup> The Commissioner for Human Rights of the Council of Europe stated that group homes could be:

> [o]ther forms of segregation placing people with disabilities in congregate care which, though situated geographically in the community (for example in a residential neighborhood) actually mirror institutional life . . . The fact of grouping people together already sets the people apart from society as a group of their own, drawing the community's gaze to disability (rather than to each individual person) and running counter to the obligation [under the CRPD] to promote 'positive perceptions and greater social awareness' towards persons with disabilities.<sup>153</sup>

<sup>&</sup>lt;sup>150</sup> See, e.g., Kanter, *supra* note 148, at 932 ("Group homes, halfway houses, quarterway houses, and board and care homes are hardly 'homes' at all. Like institutions, they segregate people with disabilities and confine them with little, if any, individual choice. The residents of such homes are seldom asked where or with whom they want to live. The places where people with mental disabilities have lived are called 'congregate living facilities,' community residences,' and 'residential living environments.' Noticeably absent in these varied descriptions is the simple word 'home.").

<sup>&</sup>lt;sup>151</sup> INCLUSION INTERNATIONAL, *supra* note 71, at 66. For people with intellectual disabilities, Inclusion International recommended that reformers "shift the focus of investments from group homes and 'institutionally' operated housing to more individualized living arrangements which might include support to live at home with a family." *Id.* at 102.

<sup>&</sup>lt;sup>152</sup> RIGHT TO LIVE INDEPENDENTLY, *supra* note 35, at 27 (citing Academic Network of European Disability Experts (ANED)).

<sup>&</sup>lt;sup>153</sup> *Id.* (citing CRPD art. 8(2)(ii)).

The Commissioner for Human Rights of the Council of Europe also warned that "[t]he larger the group, the higher the risk of resembling an institution."<sup>154</sup> Long-term outcome studies have shown that for adults, the smaller the group home the better the outcome in terms of health and quality of life.<sup>155</sup> For adults, there is a major drop-off in quality of life when there are more than six people living in a group home.<sup>156</sup> For children and adolescents, as described above, group homes present even greater risks and should never be an option – no matter what size they are.

### C. How Families Can Be Protected for Best Outcomes

There can be family-based alternatives to any form of group residential placement – even for children with complex medical needs and children in emergency situations.<sup>157</sup> Placement in kinship care or stable foster homes are familybased alternatives that have shown far better outcomes than placement in an institution.<sup>158</sup> Emergency foster care

<sup>158</sup> When children need to enter out-of-home care, permanent families can be attained for children by: 1) providing supports and remediation services to birth parents to promote reunification so birth parents can provide safely for the lifelong care of their children; 2) giving guardianship and supports as needed for kin to provide long-term care for the children; and 3) adoption by non-relative

 $<sup>^{154}</sup>$  Id.

<sup>&</sup>lt;sup>155</sup> JAMES CONROY & VALERIE BRADLY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, THE PENNHURST LONGITUDINAL STUDY: A REPORT OF FIVE YEARS OF RESEARCH AND ANALYSIS 93, 189 (1985), *available at* <a href="https://aspe.hhs.gov/pdfreport/pennhurst-longitudinal-study-combined-report-five-years-research-andanalysis">https://aspe.hhs.gov/pdfreport/pennhurst-longitudinal-study-combined-report-five-years-research-andanalysis</a> (visited May 29, 2018).

<sup>&</sup>lt;sup>156</sup> Conroy, *supra* note 90.

<sup>&</sup>lt;sup>157</sup> See Rosenau, supra note 58, at 4 (arguing that treatment can be provided within the context of a family). See also Kanter, supra note 124 (discussing alternative policy options for protecting the rights of children to live and grow up with a family). Group residential care should be distinguished from short-term medical or mental health treatment which may take place in a hospital or other medical setting while actively protecting and maintaining family ties. Even children with complex medical needs should be given the opportunity for the support they need to live with a family. See, e.g., Sandra L. Friedman & Kenneth Norwood, Out-of-Home Placement for Children with Disabilities – Addendum: Care Options for Children and Adolescents with Disabilities and Medical Complexity, 138 PEDIATRICS 1, 5 (2016) ("Family life with caring and loving caregivers should be the goal for every child with disabilities and medical complexity."). Where services for children with the greatest medical needs are lacking, "[a]dvocacy is needed to ensure that the option to live in a family home is available to all children with complex medical needs." Id.

programs and supports for extended family (kin) to care for children can be established to ensure that a child remains in a family setting even for the few days or weeks it may take to address the crisis that necessitated out-of-home placement or find a more suitable long-term placement.<sup>159</sup> The sooner the child can be brought back to a safe and nurturing family or foster family, the better the long-term outcome for that child.<sup>160</sup>

When a child has been exposed to conditions of neglect in an institution or within a family, there are evidence-based forms of treatment and support that can usually allow a child to remain with his or her family.<sup>161</sup> Rather than separating a child from his or her family, these interventions will be more effective the sooner the child can be returned to a nurturing family environment.<sup>162</sup>

Ultimately, the most effective and cost effective approach to protecting children and avoiding any form of family break-up is to provide protections and support so that they can stay in their family or among extended family.<sup>163</sup> Relying on family and friends already in the community, rather than establishing new "programs," is known as building on "natural supports."<sup>164</sup> Natural supports can more effectively bring about full inclusion in the community, and

<sup>159</sup> UNICEF IMPLEMENTATION HANDBOOK, *supra* note 8, at 51.

<sup>160</sup> See Zeanah, supra note 103, at 187.

<sup>161</sup> See The Science of Neglect, supra note 97, at 12.

<sup>164</sup> DeLashmutt, *supra* note 85, at 3.

caregivers when birth family reunification or kinship care are not possible. In a recent meta-analytic review of data from 102 research studies, when compared to children in non-relative foster care placements, children in kinship care were found to have greater continuity in placement, lower internalizing (e.g., depression) and externalizing (e.g., aggression) behavior problem scores, fewer mental health diagnoses, and higher ratings of social competence. See Marc Winokur et al., Kinship care for the safety, permanency, and well-being of children removed from the home for maltreatment, COCHRANE DATABASE OF SYSTEMATIC REVIEWS 1, 2 (2014).

<sup>&</sup>lt;sup>162</sup> See id. at 9.

<sup>&</sup>lt;sup>163</sup> See Rosenthal, supra note 62, at 332 ("In Oklahoma, for example, all institutions for children have been closed. Noting the dangers of placement in group homes, the reform was designed to ensure that all children with disabilities are able to live within a family or substitute family. Six-year outcome studies have shown that this reform has not only been successful, but it has resulted in great improvements in quality of life."); James Conroy et al., *The Hissom Closure Outcomes Study: A Report on Six Years of Movement to Supported Living*, 41 MENTAL RETARDATION VOL. 263 (2003) (describing successful results of closing institutions and moving people to supported living).

they are much more cost-efficient than creating new programs.<sup>165</sup> For children who require a higher level of professional assistance (e.g., for children who have experienced neglect), care in the context of the family is also more cost effective than breaking up a family and placing a child in a residential program.<sup>166</sup>

Innovative models of natural support for families have shown that even placement in foster care can be minimized.<sup>167</sup> Programs to support parents with disabilities have been established and provide promising models for replication globally.<sup>168</sup> Using a combination of these programs, institutions for children have been reduced or eliminated in some parts of the world.<sup>169</sup>

International experience has shown that efforts to build and staff better congregate settings for children will not produce better outcomes if children are not able to form stable emotional attachments in a family. Save the Children observed that "[i]n terms of emotional attachments, even apparently 'good quality' institutional care can have a detrimental effect on children's ability to form relationships throughout life."<sup>170</sup> Dr. Danius Puras, who later went on to be the U.N. Special Rapporteur on the Right to Health, wrote that emotional connections to family are "pre-conditions for the development of healthy attachment and trust in relations with other people in later stages of life. They cannot be secured in an institutional culture, despite all efforts to

 $<sup>^{165}</sup>$  Id.

<sup>&</sup>lt;sup>166</sup> THE SCIENCE OF NEGLECT, *supra* note 97, at 13.

<sup>&</sup>lt;sup>167</sup> CASEY FAMILY PROGRAMS, PRIORITIZING EARLY CHILDHOOD TO SAFELY REDUCE THE NEED FOR FOSTER CARE: A SCAN OF NATIONAL INTERVENTIONS (2015), *available at* <a href="https://www.casey.org/media/prioritizing-early-childhood.pdf">https://www.casey.org/media/prioritizing-early-childhood.pdf</a>.

<sup>&</sup>lt;sup>168</sup> NATIONAL COUNCIL ON DISABILITY, ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN 33 (2012), *available at* <a href="https://www.ncd.gov/publications/2012/Sep272012">https://www.ncd.gov/publications/2012/Sep272012</a> (visited June 20, 2018). See also Through the Looking Glass, <a href="https://www.lookingglass.org/">https://www.ncd.gov/publications/2012/Sep272012</a> (visited June 20, 2018). See also Through the Looking Glass, <a href="https://www.lookingglass.org/">https://www.lookingglass.org/</a> (an NGO that has worked with partners throughout the world to support parents with disabilities).

<sup>&</sup>lt;sup>169</sup> IMPLEMENTING THE GUIDELINES, *supra* note 27, at 43. See also MINISTRY FOR FOREIGN AFFAIRS SWEDEN, CHILDREN IN INSTITUTIONS: INTERNATIONAL DEVELOPMENT COOPERATION (2001), *available at* <a href="http://www.government">http://www.government</a>. se/contentassets/42b806a7f8b046468116e4f1245428b5/children-in-institutions> (visited Feb. 16, 2018); Kerryn Pollock, *Children's homes and fostering—Foster care and family homes*, THE ENCYCLOPEDIA OF NEW ZEALAND (2011), *available at* <a href="http://www.TeAra.govt.nz/en/childrens-homes-and-fostering/page-4">http://www.TeAra.govt.nz/en/childrens-homes-and-fostering/page-4</a>> (visited Feb. 18, 2018).

<sup>&</sup>lt;sup>170</sup> SAVE THE CHILDREN, *supra* note 51, at 13.

invest financial and human resources in those facilities."<sup>171</sup> Lessons learned from well-meaning but ultimately misguided efforts to improve institutions should be extended to similar efforts to create family-like residential care programs. These efforts are no doubt well-intentioned, but there is no substitute for growing up with the love and care of a family.

# III. RIGHT TO FAMILY UNDER THE CRPD

The international move to draft the CRPD derived from a recognition that, while "the existing human rights system was meant to promote and protect" the rights of all people, including people with disabilities, "the existing standards and mechanisms have in fact, failed to provide adequate protections in the specific case of persons with disabilities."<sup>172</sup> It is striking that such a convention never defines what constitutes a "disability."<sup>173</sup> In part, this is because the CRPD brings an approach to protection against discrimination that does not focus on the limitations of the individual but on the barriers that society creates to full participation. This approach, known as the "social model" of disability, is represented in the preamble of the CRPD, which states that "disability results from the interaction between impairments attitudinal persons with and and environmental barriers that hinders their full and effective participation in society on an equal basis with others."<sup>174</sup>

The social model of disability underlies the approach the CRPD takes to protect the right of full inclusion in society. The right to live with a family is not dependent on the limitations of the particular individual; it is a guarantee that must be enforced by creating a fully inclusive and supportive society.

The CRPD was not originally intended by the U.N.

<sup>&</sup>lt;sup>171</sup> OHCHR EUROPE REGIONAL OFFICE, THE RIGHTS OF VULNERABLE CHILDREN UNDER THE AGE OF THREE: ENDING THEIR PLACEMENT IN INSTITUTIONAL CARE 19 (2011).

<sup>&</sup>lt;sup>172</sup> MacKay, *supra* note 47, at 326. CRPD Article 1 states that the treaty's purpose is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities." CRPD, *supra* note 5, art. 1.

<sup>&</sup>lt;sup>173</sup> For background on the CRPD's drafting committee's decision not to include a definition of disability in the CRPD, see KANTER, *supra* note 47, at 8-9.

 $<sup>^{174}</sup>$  CRPD, supra note 5, pmbl  $\P$  e. The same language is used in the Article 1 description of the purpose of the convention.

General Assembly to create new rights but to ensure that existing rights were applied to people with disabilities who were long overlooked by international law.<sup>175</sup> As described by CRPD Committee member Rosemary Kayess, this principle has come to be understood as something of a legal fiction, as the establishment of new protections for people overlooked by human rights law effectively extends existing rights.<sup>176</sup>

When the U.N. General Assembly created an Ad Hoc Committee to draft the CRPD, it called on the drafters to create a new convention based on a "holistic approach in the work done in the fields of social development, human rights, and non-discrimination."177 The new protections established by the CRPD are consistent with the lessons from scientific research summarized in Part II above. But most importantly, the CRPD was "informed by the experiences of persons with disabilities worldwide."178 The right to live and make choices in the community, as recognized by Article 19, was influenced by the hard-won personal experience of people with disabilities who have proven that they could live in the community when barriers are removed, when society is inclusive, and appropriate support is available.<sup>179</sup> As stated by Laurie Ahern, then co-director of the National Empowerment Center, arguing that people diagnosed with major mental illness can fully recover: "we are the evidence."180 The drafting of the CRPD was also influenced

 $^{178}$  MacKay, supra note 47, at 327.

<sup>179</sup> See KANTER, supra note 47 (summarizing discussions at the Ad Hoc Committee that drafted the CRPD and the influence of recent experience with community integration).

<sup>180</sup> Laurie Ahern, Testimony before the President's New Freedom Commission on Mental Health, Apr. 3, 2003 (on file with author). *See also* Daniel

<sup>&</sup>lt;sup>175</sup> Kayess, supra note 19, at 20. See also KANTER, supra note 47, at 9.

<sup>&</sup>lt;sup>176</sup> Kayess, *supra* note 19, at 20 ("Given that the *raison d'etre* for the development of the [CRPD] was that existing human rights instruments have failed persons with disability, to say the very least, it is paradoxical to propose that these instruments nevertheless provide the necessary scope and content from which to derive a blue-print that will secure their rights in the future. However, despite the logical incoherence of this proposition, this was the unchallenged political/administrative framework within which the CRPD was developed.").

<sup>&</sup>lt;sup>177</sup> Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities ¶1, G.A. Res. 56/168, at 2, U.N. GAOR, 56th sess., 88th plen. mtg., Agenda Item 119(b), U.N. Doc. A/56/168 (2001). For background on the drafting process and development of the convention, see Tara Melish, The U.N. Disability Convention: Historic Process, Strong Prospects, and Why the U.S. Should Ratify, 14 HUM. RTS. BRIEF (2007).

by the practical experience of advocacy organizations, such as Disability Rights International (DRI), committed to rights enforcement and aware of the ways governments would use general policy commitments to avoid truly enforceable, legal requirements.<sup>181</sup> The CRPD is unique in the development of international law in that the community of people affected by its rights were active in its drafting and development, and it reflects their experiences.<sup>182</sup>

CRPD Article 7(1) requires states to "ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children." Thus, if reform programs are closing down institutions and integrating non-disabled children into the community, it is a form of discrimination to deny family support and community integration to children with disabilities.<sup>183</sup>

General Comment No. 5 describes the right to community integration as one of the most inter-sectional because it affects almost every other right established in the convention. At the same time, the right to community integration is not considered a new right established by the convention. Rather, it is seen as a protection against discrimination that allows people with disabilities to enjoy the same right to be part of society as is enjoyed by all other people. And for children, as General Comment No. 5 has said, "the core of the right to live independently and be included in the community entails a right to grow up in a family."<sup>184</sup> Flowing from the core right to live and grow up in a family is that no half-measures can substitute for its full implementation: "Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. 'Family-like' institutions are still institutions and are no substitute for care by a family."185

In her recent report on children deprived of liberty, U.N. Special Rapporteur Catalina Devandas agrees with this finding and analysis, noting that, for children, "[t]he

A. Fisher & Laurie Ahern, *Evidence-Based Practices and Recovery*, 53 PSYCHIATRIC SERVICES 632 (2002) (letter to editor), *available at* <<u>https://ps.psychiatryonline.org/doi/abs/10.1176/appi.ps.53.5.632-a></u>.

<sup>&</sup>lt;sup>181</sup> Melish, *supra* note 46, at 72-74.

<sup>&</sup>lt;sup>182</sup> KANTER, supra note 47, at 40.

 $<sup>^{183}</sup>$  General Comment No. 5, supra note 36,  $\P$  71.

<sup>&</sup>lt;sup>184</sup> *Id.* ¶ 37 (emphasis added).

<sup>&</sup>lt;sup>185</sup> *Id.* ¶ 16(c).

detrimental effects of institutionalization on their development, even when placed in small residential homes or 'family-like' institutions, have been vastly demonstrated."<sup>186</sup>

# A. Protection of the Family for Children with and without Disabilities

For children, the right to live in the community under Article 19 is closely linked with—and greatly strengthens the respect for home and family in Article 23. Article 23(4) has language that exactly tracks that of the CRC Article 9, stating that:

> States parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interest of the child.

Through Article 23(4), the CRPD opens the scope of the convention as broadly as the CRC. Like the CRC, this provision refers to "children" and not just "children with disabilities" or "persons with disabilities" (as is used throughout the rest of the CRPD). Article 23(4) then adds the following line: "In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents."

This provides key protections to children with disabilities who may not be separated from their parents because of their disability. But more broadly, this language also protects the rights of children without disabilities from improper family separation if their parents happen to have a disability. One could interpret this as a protection for parents with disabilities that happens to create peripheral effects on their non-disabled children. Or one can read in this exactly what the text says: it creates protections for children.

There are many forms of discrimination against parents with disabilities that lead to the improper confinement of their children (described previously in Part I). In many such cases, if parents had the support they

<sup>&</sup>lt;sup>186</sup> 2019 Special Rapporteur on Disability Report, *supra* note7, ¶ 19.

needed, it would not be necessary for families to be broken up and children to be placed in institutions. This points to another way that the CRPD creates increased protections to non-disabled individuals. The enforcement of Article 19 for parents with disabilities results in opportunities for families to stay together. Enforcement of Article 19 for adults ends up creating essential protections for children, whether or not they have a disability.

# B. The CRPD Does Not Allow for Institutional Placement

The language of Article 23(5) goes on to establish that, "where the immediate family is unable to care for a child with disabilities," States Parties shall "undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting." When read in conjunction with Article 19, Article 23(5) is stronger than the CRC. While Article 23 requires governments to "make best efforts," CRPD Article 19 does not allow governments to give up on the community integration of any child. And when, after best efforts, it is impossible for the child to stay with the immediate family, that child still has the right to live and grow up with a family setting. As interpreted by General Comment No. 5, a "family setting" must be understood as a family or family-based care and not residential care or a group home.

While it does not explicitly ban placement in institutions, the plain language of Article 23(5) (even read without the benefit of General Comment No. 5) does not allow for institutional or residential placement as a way to protect the rights of the child. Care must be found "within the wider family" or "within the community in a family setting." There is no language, as in the CRC, about placement in "suitable institutions."<sup>187</sup>

While CRPD Article 23(4) affords rights to all children, Article 23(5) references only "children with disabilities." To the extent that the CRPD is viewed as extending the same rights to children with disabilities as are enjoyed by all other children, CRPD Article 23(5) should be

<sup>&</sup>lt;sup>187</sup> This is also true of CRPD General Comment No. 5. The General Comment supportively cites the work of the Committee on the Rights of the Child on the need for family support and deinstitutionalization, but calls only for placement in "family, extended family or foster care" and not any alternatives. *See* General Comment No. 5, *supra* note 36, at ¶ 12.

viewed as the specific application of a general protection. If children with disabilities have these rights, it is because *all* children have these rights. Given what we know about the dangers of institutional placement for all children, it would make no sense for children with disabilities to have a stronger protection for the right to grow up with a family than non-disabled children. Research shows that placement in institutions or group homes outside a family is also destructive for children who have no prior mental or physical disability.<sup>188</sup> A new or updated General Comment by the CRC would be of great value to explain what should be obvious: these principles apply to all children equally – whether or not they have a label of disability.

The practice of the U.N. Committee on the Rights of Persons with Disabilities (CRPD Committee) supports this approach. Even before the CRPD Committee adopted General Comment No. 5, the Committee had begun to incorporate these strong new protections into its work in reviewing practices of States Parties. In September 2016, the Committee asked Guatemala to "abolish institutionalization" of children.<sup>189</sup> This Concluding Observation appears to endorse a moratorium on new placements in institutions. The Committee's statement uses the term "children" and not "children with disabilities," reinforcing the ideal that all children have a right to these protections. In 2015, the Committee similarly called on Croatia to "implement a moratorium on new admissions to institutions and strengthen its efforts to provide psychological, financial, and social services support measures to families."<sup>190</sup> The CRPD Committee's call for a moratorium on admissions in Croatia is not limited to children with disabilities.

In reviewing other country reports, most of the language of the CRPD Committee does address the specific concerns of children with disabilities – but it takes a strong stand against any form of institutional placement. The

 $<sup>^{188}</sup>$  Dozier et al., supra note 43, at 221.

<sup>&</sup>lt;sup>189</sup> Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Guatemala* ¶ 54(d), U.N. Doc. CRPD/C/GTM/CO/1 (2016), *available at* <a href="http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=En>">http://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Lang=CRPD/C/GTM/CO/1&Lang=CRPD/C/GTM/CO/1&Layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GTM/CO/1&Layouts/treaty

<sup>&</sup>lt;sup>190</sup> Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of Croatia* ¶12, U.N. Doc. CRPD/C/HRV/CO/1 (2015), *available at* <a href="https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHRV%2fCO%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2f1&Lang=en>">https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2f1&Lang=en>">https://tbinternet.okchr.org/\_layo

Committee also called on the Czech Republic to "abolish" institutions for children with disabilities.<sup>191</sup> In the CRPD Committee's review of Armenia in 2017, the Committee expressed concern about children in orphanages and schools about "transresidential and warns institutionalization from one institution to another under the guise of deinstitutionalization..."192 Instead, the Committee calls for support of families and early intervention programs.<sup>193</sup> Consistent with CRPD Article 23(5), the CRPD Committee does not call for placement in "suitable institutions" or residential care of any kind.<sup>194</sup>

In its January 2017 report on human rights and mental health, the U.N. Office of the High Commissioner on Human Rights (OHCHR) cites the CRPD and calls on governments to "ensure that deinstitutionalization in the case of children is focused on reintegrating them into a family rather than into a smaller institution."195 The OHCHR also refers to "children" and not just children with disabilities in calling on governments to "seek alternative family placement rather than any form of residential care for children who must be removed from their own family."<sup>196</sup> In the same paragraph, however, the OHCHR calls for "a moratorium on new admissions of children with disabilities in institutions."<sup>197</sup> When drawing on the CRPD, it is natural to focus on the special concerns of children with disabilities. It makes no sense to expose children without a label of disability to the dangers of placement that would not be acceptable for their peers.

In March 2018, the CRPD Committee issued General

 $^{193}$  Id.

 $^{194}$  The CRPD calls for "resettlement in family settings, including by promoting foster care and providing appropriate community-based support to parents." *Id.* ¶ 12(a).

<sup>195</sup> Report of the United Nations High Commissioner for Human Rights on Mental Health and Human Rights ¶ 58, U.N. Doc. A/HRC/34/32 (2017).

<sup>&</sup>lt;sup>191</sup> Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Initial Report of the Czech Republic* ¶40, U.N. Doc. CRPD/C/CZE/CO/1 (2015), *available at* <a href="http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fCZE%2fC">http://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fCZE%2fC O%2f1&Lang=en>.

<sup>&</sup>lt;sup>192</sup> Committee on the Rights of Persons with Disabilities, *Concluding Observation on the Initial Report of Armenia* ¶11, U.N. Doc. CRPD/C/ARM/CO/1 (2017), *available at <*https://tbinternet.ohchr.org/\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fARM%2fCO%2f1&Lang=en>.

 $<sup>^{196}</sup>$  Id.

 $<sup>^{197}</sup>$  Id.

Comment No. 6 on equality and non-discrimination. The Committee calls on governments to "...address violence and institutionalization of children with disabilities, who are denied the right to grow up in their families as a matter of discrimination."<sup>198</sup> If the right to family is understood as a protection against discrimination, then children with and without disabilities must enjoy the same right. The CRPD Committee may not consider it within its mandate to define the rights of children without a disability label, but the CRC Committee would do well to clarify these general principles.

#### C. Enforcement Obligations

The requirement of taking "best efforts" in CRPD Article 23 must not be taken to undermine the enforceability of the right to family under the CPRD. The right to family for children is immediately enforceable as a protection against discrimination. And, to the extent that social programs must be established for its full implementation, governments are required to take immediate action to adopt laws and policies that will bring about its full enforcement.

The CRPD includes obligations historically understood as "civil and political rights" – subject to immediate obligations of full enforcement – and "economic and social rights" subject to "progressive enforcement" over time.<sup>199</sup> This dichotomy is often misunderstood, because progressive enforcement has always included immediate obligations to move "as expeditiously and effectively as possible toward the goal of full realization of rights."<sup>200</sup>

Today, all human rights are recognized to be indivisible, interrelated, and interdependent so it may be impossible to categorize a right within one category or

 $<sup>^{198}</sup>$  Committee on the Rights of Persons with Disabilities, General Comment No. 6 on equality and non-discrimination ¶ 38, U.N. Doc. CRPD/C/GC/6 (2018), available at <a href="https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en>">https://tbinternet.ohchr.org/layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=trants/</ap>

<sup>&</sup>lt;sup>199</sup> See Stephen Marks, The Past and Future of the Separation of Human Rights into Categories, 24 MARYLAND J. INT'L L., 209, 227 (2009) (describing the historical understanding that "civil and political rights were deemed to be immediately enforceable, whereas economic, social, and cultural rights were deemed to be subject to progressive implementation.").

<sup>&</sup>lt;sup>200</sup> Comm. on Econ., Social & Cult. Rts., General Comment No. 3: The Nature of States Parties Obligations ¶ 9, U.N. Doc. E/1992/23 (1990) [hereinafter General Comment No. 3].

another,<sup>201</sup> and the CRPD preamble specifically reaffirms this principle.<sup>202</sup> As a reflection of this, the CPRD introduces new language to emphasize that any rights that may be subject to "progressive enforcement" are also enforced "without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law."<sup>203</sup>

The right to live in the community under CRPD Article 19 is a good example of a "hybrid" right – a protection against discrimination that may also require progressive realization to fully implement.<sup>204</sup> To the extent that immediate action can be taken to end discrimination, governments are under an obligation to do so. To the extent that investments must be made to plan, allocate resources, and create new services, progressive implementation must take place over time. Just because a right is subject to progressive realization does not mean that it is anything less than an immediate right. Immediate action must be taken to bring about full enforcement.

In General Comment No. 5, the CRPD Committee provides guidance as to the obligation to implement and enforce the right to community integration under CRPD Article 19. The CRPD Committee points out that full realization of these rights "requires structural changes that may need to be taken in stages, no matter whether civil and political or social economic and cultural rights are at stake."<sup>205</sup> This means adopting "clear and targeted strategies for de-institutionalization with specific timeframes and adequate budgets in order to eliminate all forms of isolation ...."<sup>206</sup> When it comes to steps toward deinstitutionalization, the CRPD Committee specifies to States Parties that "steps must be taken immediately or within a reasonably short period of time. Such steps should be deliberate, concrete, targeted and use all appropriate means."<sup>207</sup>

While restructuring social service systems inevitably

<sup>&</sup>lt;sup>201</sup> Marks, *supra* note 199, at 214.

<sup>&</sup>lt;sup>202</sup> CRPD, *supra* note 5, pmbl. ¶ c.

<sup>&</sup>lt;sup>203</sup> *Id.* art. 4(2). *See also* Andrea Broderick, *Article 4: General Obligations, in* CRPD COMMENTARY, *supra* note 6, at 132 (discussing the drafting history and meaning of CRPD article 4(2) and describing efforts to improve and clarify protections for progressive enforcement in such conventions as the CRC).

 $<sup>^{204}</sup>$  Right to Live Independently, supra note 35, at 21.

 $<sup>^{205}</sup>$  General Comment No. 5, supra note 36,  $\P$  7.

<sup>&</sup>lt;sup>206</sup> Id. ¶ 98(g).

<sup>&</sup>lt;sup>207</sup> *Id.* ¶ 41.

takes time, protections against discrimination can be immediately enforceable. In Article 5, the CRPD makes clear that governments must not only prohibit discrimination, they must "guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds." Thus, in addition to planning for and financing reform, General Comment No. 5 states that governments are under an obligation to "enact and enforce laws, standards, and other measures with the purpose to make local communities and environment . . . accessible to all persons with disabilities."<sup>208</sup>

General Comment No. 5 also recognizes the importance of high priority "core" rights to protect individuals against discrimination.<sup>209</sup> The CRPD Committee specifies that "[f]or children, the core of the right to live independently and be included in the community entails a right to grow up in a family."<sup>210</sup> Core rights are the "minimum essential levels of each of the rights."211 As with other rights to be achieved through progressive realization, these rights must be enforced through actions that are "deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized in the The Covenant."212 CRPD Committee specifies that governments must ensure that "core elements of Article 19 are always respected, particularly in times of financial or economic crisis."213

A recent legal analysis by top experts in international law has argued that *any* form of funding for residential institutions represents a form of discrimination and violates international law.<sup>214</sup> These experts point out that some

<sup>&</sup>lt;sup>208</sup> *Id.* ¶ 98(b).

 $<sup>^{209}</sup>$  See General Comment No. 5, supra note 36,  $\P\P$  38, 43, 45 (describing Committee's use of term "core" rights).

<sup>&</sup>lt;sup>210</sup> *Id.* ¶ 37.

<sup>&</sup>lt;sup>211</sup> General Comment No. 3, supra note 200, ¶ 1.

 $<sup>^{212}</sup>$  Id. ¶ 2. See Marks, supra note 199, at 201, 228 (referring to rights subject to immediate enforcement even if they require resources and programs to be developed and taking the position that, given the inter-divisibility of rights, the dichotomy between "civil and political" and "economic and social" rights has "lost its pertinence").

<sup>&</sup>lt;sup>213</sup> General Comment No. 5, supra note 36, ¶ 38.

<sup>&</sup>lt;sup>214</sup> Gerard Quinn et al., Segregation and segregated facilities as prima facie form of discrimination: The impermissibility of using the ESIF to invest monies in long term care residential institutions for persons with disabilities (2018) (unpublished memorandum on file with the author).

elements of CRPD Article 19 (paragraphs 2 and 3), which require the provision of social services necessary for community integration, could be considered subject to the principle of progressive achievement.<sup>215</sup> These experts consider, therefore, whether the creation of smaller residential institutions could be considered a form of progressive achievement on the way toward full implementation of the Article 19 integration mandate. However, the experts strongly repudiate this argument:

> One thing is abundantly clear: the creation of (and the expenditure of funding on) new long term care residential institutions (large, or small, or smaller) is not permissible. Investing in any institution  $\mathbf{is}$ presumptively discriminatory. As the U.N. Committee puts it - while the programme to deinstitutionalize is subject to 'progressive achievement' the actual end goal of deinstitutionalization ('replacement' in the words of the Committee) is nonnegotiable. . . . [T]ransitioning away from longterm care residential institutions requires foresight and planning. The planning must assume closure – and not way stations toward closure."216

This analysis is relevant to the economic arguments often put forth to justify creating smaller institutions and group homes. As a legal matter, small group homes cannot be justified as a step toward full integration. As a practical matter, what is created as a "temporary step" until full enforcement is made possible can easily become permanent. And when it comes to maximizing the impact of a limited budget, full integration into a family is less costly and more cost-effective in the long-term.<sup>217</sup> Even if short-term economic imperatives favored placement in smaller institutions and group homes, however, such placement must be seen as a form of discrimination impermissible under international law.

<sup>&</sup>lt;sup>215</sup> *Id.* at 14.

<sup>&</sup>lt;sup>216</sup> Id. at 15.

 $<sup>^{217}</sup>$  General Comment No. 5, *supra* note 36, ¶ 5. *See generally* JIM MANSELL ET AL., DEINSTITUTIONALIZATION AND COMMUNITY LIVING – OUTCOMES AND COSTS: REPORT OF A EUROPEAN STUDY (VOL. 2) (2007).

UN Special Rapporteur on Disability Catalina Devandas also takes a strong stand against the use of residential care and group homes as part of a strategy on deinstitutionalization. She states that "[d]einstitutionalization strategies must refrain from simply relocating individuals into smaller institutions, group homes, or different congregated settings."<sup>218</sup>

The creation of group homes or residential care cannot be legally justified under the CRPD as a step toward the progressive enforcement of the right to live with a family. Meeting the duty of immediate action toward full enforcement requires that resources be directed toward preserving and protecting families. New resources must be used to create family-support programs and emergency foster care so that children now in institutions can be integrated into families as soon as possible.

#### IV. CRITIQUE OF THE CHILDREN'S RIGHTS FRAMEWORK

With the adoption of the CRPD, it is necessary to reexamine how interpretations of the U.N. Convention on the Rights of the Child (CRC) might change in light of newly recognized protections for children and adults with disabilities. In adopting the CRPD, the U.N. recognized that earlier interpretations of human rights treaties may have been limited in their understanding of disability issues – and this is no less true of the CRC.<sup>219</sup> UNICEF's Implementation Handbook for the Convention on the Rights of the Child identifies the right to family (along with the right to inclusive education) as one of two main areas where the CRPD "provisions go further" than the CRC in protecting children's rights.<sup>220</sup>

# A. Convention on the Rights of the Child (CRC)

As a human rights convention that has been ratified by every country of the world except the United States, the CRC has achieved "unrivalled legal status" in influencing national laws and international policies and development

<sup>&</sup>lt;sup>218</sup> 2019 Special Rapporteur on Disability Report, *supra* note 7, ¶ 67.

<sup>&</sup>lt;sup>219</sup> SAVE THE CHILDREN, SEE ME HEAR ME: A GUIDE TO USING THE U.N. CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES TO PROTECT CHILDREN 15 (2009).

<sup>&</sup>lt;sup>220</sup> UNICEF IMPLEMENTATION HANDBOOK, *supra* note 8, at 324.

assistance to help children around the world.<sup>221</sup> The CRC "recognizes children as subjects of rights and insists on respect for children as actors in the exercise of their rights, and participants in all matters affecting them, challenges the traditional perception and status of children as lesser individuals than adults."<sup>222</sup>

Given the innovative new approach taken by the CRC, and the importance of the CRC Committee's impressive work in holding governments accountable for implementing these new rights, it may come as a surprise to children's rights activists that the convention, in some key respects, now lags behind the CRPD. But the CRC's framers understood that practices would evolve and standards must reflect those changes. One role of the Committee on the Rights of the Child is to study those changes and issue updated General Comments that reflect best practices.<sup>223</sup> If a particular country has a law that is stronger than the CRC, Article 41 of the CRC says that the stronger practice should prevail. Under Article 45 of the CRC, this principle also applies to other international standards or rulings of "other competent bodies" of the United Nations.<sup>224</sup> Thus, if General Comment No. 5 of the CRPD calls for a higher standard of protection based upon recent research and experience, it is incumbent upon the CRC Committee to update its General Comments on the CRC to reflect this development.

The shift toward children as holders of rights rather than objects of protection parallels what is commonly referred to as a paradigm shift bought about by the CRPD for individuals with disabilities.<sup>225</sup> The CRPD appears to take this principle one step further – guaranteeing children a right to *live* in the community rather than a right to protections, services, or special protections "conducive to the

 $^{225}$  KANTER, supra note 47, at 46 (describing the "paradigm shift" in understanding of human rights as a result of the CRPD).

<sup>&</sup>lt;sup>221</sup> Ursula Kilkelly, *Translating International Children's Rights Standards into Practice: The Challenge of Youth Detention, in* CENTER FOR HUMAN RIGHTS & HUMANITARIAN LAW ANTI-TORTURE INITIATIVE, PROTECTING CHILDREN AGAINST TORTURE IN DETENTION 39-41 (2017).

<sup>&</sup>lt;sup>222</sup> SAVE THE CHILDREN, *supra* note 219, at 15.

<sup>&</sup>lt;sup>223</sup> Eugeen Verhellen, *The Convention on the Rights of the Child: Reflections from a Historical, Social Policy, and Education Perspective, in* ROUTLEDGE INTERNATIONAL HANDBOOK OF CHILDREN'S RIGHTS STUDIES 43, 52 (Wouter Vandenhole et al., eds. 2015).

 $<sup>^{224}</sup>$  CRC, supra note 4, art.45.

child's achieving the fullest possible social integration."<sup>226</sup> Article 23 of the CRC is "riddled with qualification and limitations with regard to resources" limiting the enforceability of the right of children to receive the services necessary to live in the community.<sup>227</sup> While Article 23(1) savs that children with disabilities "should" live in the community. it does not provide the same kind of absolute requirement that it includes for other rights – such as the obligation on governments to prohibit and protect against child abuse.<sup>228</sup> As described above. "progressive realization" includes an obligation to take immediate action to bring about full enforcement over time. Yet some leaders of the children's rights field have interpreted the CRC to mean even less than that – a policy recommendation rather than a truly enforceable legal framework.<sup>229</sup>

The CRC's most significant limitation on the right to live and grow up in a family is Article 20, which permits children to be placed in "suitable institutions." This language is problematic now that we know institutions are inherently *not* suitable for children. Discussing the reference to "suitable institutions" in Article 20, the U.N. Office of the High Commissioner on Human Rights observed:

> [T]he wording 'in suitable institutions' needs clearer interpretation to avoid misuse as a justification for institutional care. The CRC was drafted during the 1980s, when the issue of institutionalization was not perceived as one of the most serious concerns. The then-Communist countries of Eastern and Central Europe, where institutional placement of children was part of the ideology governing

<sup>&</sup>lt;sup>226</sup> CRC Article 23(1) on the rights of children with disabilities guarantees "conditions" that "promote self-reliance and facilitate the child's participation in the community." CRC, *supra* note 4, art. 23(1). Living in the community is not fully guaranteed. Article 23(3) is framed as a right to services (e.g. "education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities") in a manner "conducive to the child's fullest possible social integration." *Id.* art. 23(3).

<sup>&</sup>lt;sup>227</sup> Ursula Kilkelly, *Disability and Children: The Convention on the Rights of the Child (CRC), in* HUMAN RIGHTS AND DISABILITY: THE CURRENT USE AND FUTURE POTENTIAL OF UNITED NATIONS HUMAN RIGHTS INSTRUMENTS IN THE CONTEXT OF DISABILITY 119, 120 (Gerard Quinn et al., eds. 2002).

 $<sup>^{228}</sup>$  Id.

<sup>&</sup>lt;sup>229</sup> See text accompanying notes 21-22 supra.

child-protection systems, were among its active drafters. Therefore, it is understandable that an elastic definition of 'suitable institutions' might have represented the lowest common denominator in that geopolitical situation.... Today, more than two decades after the adoption of the CRC, it is appropriate to raise the question of whether institutional care can be a "suitable option" for children at all especially for children under three years of age; whether any exceptions are acceptable; and whether it is time to seriously consider its elimination.<sup>230</sup>

These words were written in 2011, shortly after the adoption of the CRPD, and seem to anticipate the later language of General Comment No. 5. U.N. Special Rapporteur on Disability, Catalina Devandas, in her recent report on deprivation of liberty has also called into question CRC Article 20:

> The notion of 'suitable institutions" under Article 20 of the Convention on the Rights of the Child and the Guidelines for the Alternative Care of Children should be reviewed under the higher standards upheld by the Convention on the Rights of Persons with Disabilities. As Article 41 of the [CRC] recognizes, its implementation should not affect any provisions of international law that are more conducive to the realization of the rights of the child.<sup>231</sup>

The problems with the language of the CRC can be resolved with new, updated interpretations from the CRC that address these issues. The CRC recognizes the core principle of the best interest of the child.<sup>232</sup> In light of new research that it is not in the best interest of the child to be placed in group care, this principle alone should override any interpretation of the CRC that might allow such placement.

 $<sup>^{230}</sup>$  OHCHR EUROPE REGIONAL OFFICE, supra note 171, at 10-11 (emphasis in the original).

<sup>&</sup>lt;sup>231</sup> 2019 Special Rapporteur on Disability Report, *supra* note 7, ¶ 51.

<sup>&</sup>lt;sup>232</sup> CRC, *supra* note 4, art. 3(1).

#### B. General Comment No. 9

The "general comments" of treaty-based bodies, like the U.N. Committee on the Rights of the Child, are nonbinding legal instruments.<sup>233</sup> They are intended, however, to assist in the interpretation of what binding human rights conventions require. The Committee on the Rights of the Child drafted General Comment No. 9 on children with disabilities at the same time the CRPD was being drafted, but it does not reflect the developments in rights protection contained in the CRPD.

CRC General Comment No. 9 was drafted at the same time as the CRPD was being developed, and some of the innovative concepts developed by CRPD's drafters were included in the text. This includes a reference to the social model of disability – stating that people with disabilities include those with "impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."234 General Comment No. 9 describes this as a "definition" of disability – which it is *not* in the CRPD, and unfortunately the social model of disability is not reflected in its language and protections. <sup>235</sup> General Comment No. 9 still links the right to family to the provision of "special care" that would "aim at the maximum inclusion of those children in society."236 General Comment No. 9 is still framed as a right to services to the extent of available resources, rather than a right to live in the community and a right to grow up with a family.

General Comment No. 9 strongly values family placement and recognizes that children with disabilities are "best cared for and nurtured within their own family . . . ."<sup>237</sup> It recognizes the "role of the extended family" which is "one

<sup>&</sup>lt;sup>233</sup> UNESCO, More About the Nature and Status of the Legal Instruments and Programmes <a href="http://www.unesco.org/new/en/social-and-human-sciences/">http://www.unesco.org/new/en/social-and-human-sciences/</a> themes/advancement/networks/larno/legal-instruments/nature-and-status/>. (visited Apr. 20, 2019). While they are non-binding, general comments are

 <sup>(</sup>distribution of the legal significance of treaty-based committee general comments).
<sup>234</sup> CRC General Comment No. 9, *supra* note 16, ¶ 7.

<sup>&</sup>lt;sup>235</sup> These words appear as part of the "purpose" in CRPD Article 1. CRPD, supra note 5, art. 1. The CRPD specifically avoided adopting a definition of disability which might limit its application.

<sup>&</sup>lt;sup>236</sup> General Comment No. 9, *supra* note 16, ¶ 11.

<sup>&</sup>lt;sup>237</sup> *Id.* ¶ 41.

of the best alternatives for childcare" which "should be strengthened and empowered to support the child and his or her parents or others taking care of the child."<sup>238</sup> The General Comment calls for governments to replace institutions with "families, extended families, and foster care."<sup>239</sup> With reference to institutions, the Committee on the Rights of the Child:

> urges States parties to use the placement in institution only as a measure of last resort, when it is absolutely necessary and in the best interests of the child. It recommends that the States parties prevent the use of placement in institution merely with the goal of limiting the child's liberty or freedom of movement. In attention addition. should be paid to transforming existing institutions, with a focus on small residential care facilities organized around the rights and needs of the child, to developing national standards for care in institutions, and to establishing rigorous screening and monitoring procedures to ensure effective implementation of these standards.<sup>240</sup>

In light of a strong body of research showing that group care is "inherently detrimental," it should no longer be possible to say that placement is in the child's "best interest." Institutional placement is, at best, the "least detrimental" placement in an inadequate system. The suggestion that states "transform" institutions into residential programs "organized around the rights and needs of the child" directly contravenes CRPD General Comment No. 5. This General Comment recognizes that smaller facilities can be equally as dangerous as larger institutions and are no substitute for living and growing up in a family.<sup>241</sup> We now know that efforts to improve and make institutions "suitable" are inherently doomed to failure and will never get children what they truly need – the emotional bonds that can only come with growing up in a family. The term "transforming institutions" has allowed governments to use it as "code" for

<sup>&</sup>lt;sup>238</sup> Id. ¶ 45.

<sup>&</sup>lt;sup>239</sup> *Id.* ¶ 49.

 $<sup>^{240}</sup>$  Id.  $\P$  47 (emphasis added).

<sup>&</sup>lt;sup>241</sup> General Comment No. 5, *supra* note 36, ¶ 16(c).

spending more money to renovate and rebuild institutions where children with disabilities remain.<sup>242</sup> CRPD General Comment No. 5, in contrast, prohibits new investments in institutions except to protect the immediate safety of children.<sup>243</sup>

The first component of General Comment No. 9, the last resort/best interest standard, is intended as a guidance to governments to avoid unnecessary placement of children. Ironically, this principle is well ahead of actual practice in most of the world. If this principle were actually implemented, it would have a vast impact on all the discretionary placement of children in most of the world's institutions. It arguably would ban new construction of orphanages or institutions where funds could, instead, be used to improve protections for children to stay with families.

The basic problem with the last resort standard has been described above: it provides no protection against improper confinement in a situation in which there are few or inadequate family-based programs. For children with no place to go and no support in the community, the institution is always the last resort. But this does not mean that it is in their "best interest." The last resort standard is especially dangerous for children with disabilities in places where community-based services and supports are lacking. Instead of obliging governments to create family support programs, General Comment No. 9 can be and is used around the world by governments to justify the placement of children in large or small institutions when no alternatives exist.

Seen against the backdrop of the rights established in the CRPD, the last resort standard is not really an expression of a right of the child as much as it is a direction to governments in how to mitigate damage to the child when those rights have not been fully enforced. Any time a government has to invoke the last resort standard, authorities have already failed the child by not creating the protections for families needed to prevent separation, or not

<sup>&</sup>lt;sup>242</sup> In Ukraine, DRI learned of a World Bank program to support deinstitutionalization of orphanages. For children without disabilities, this meant re-integration into families. Due to the lack of community and familysupport programs for children with disabilities, the program allowed for "transforming" institutions for children with disabilities into family-like environments. After DRI exposed the discriminatory program, the World Bank backed down in its plan. *See* DISABILITY RIGHTS INTERNATIONAL, NO WAY HOME: THE EXPLOITATION AND ABUSE OF CHILDREN IN UKRAINE'S ORPHANAGES 11 (2015).

 $<sup>^{243}</sup>$  General Comment No. 5, supra note 36,  $\P$  49.

creating the emergency foster care systems to avoid even temporary placement in an institution.

To the extent that the last resort standard guides governments with inadequate service systems, those governments must also be held to the standard described by U.N. Special Rapporteur on Torture Juan E. Méndez. Since any confinement of children subjects them to an increased risk of torture, Méndez states that any such placement must only be for "the shortest possible period of time... and limited to exceptional cases."<sup>244</sup>

The U.N. Special Rapporteur on Disability's analysis on the right to protection from the deprivation of liberty is also a powerful answer to the last resort standard. As she states:

Placing a person with disabilities into an institution, either without their consent or with the consent of a substitute decision-maker, contradicts the right to personal liberty and the right to live independently in the community (art. 19). The failure of the State to provide persons with disabilities with the appropriate support to live independently in the community cannot constitute a legitimate ground for deprivation of liberty. Likewise, placing a child outside the family in an institution or residential home on the basis or an actual or perceived impairment of the child and/or of his parents or legal guardian or her is discriminatory and, therefore, arbitrary and  $unlawful.^{245}$ 

## C. Guidelines for Alternative Care

The U.N. Guidelines for Alternative Care were adopted after General Comment No. 9 and have played a role in shaping government policies to promote a shift away from institutions.<sup>246</sup> The Guidelines call on every country to develop a plan for the "progressive elimination" of

 $<sup>^{244}</sup>$  Méndez 2015 Report, supra note 63,  $\P$  72.

 $<sup>^{245}</sup>$  2019 Special Rapporteur on Disability Report, supra note 7,  $\P$  48.

 $<sup>^{246}</sup>$  See IMPLEMENTING THE GUIDELINES, supra note 27, at 46 (describing the use of the Guidelines to influence government plans toward reform).

institutions for children.<sup>247</sup> To achieve this goal, the Guidelines call on governments to address the "root causes of child abandonment" by pursuing "policies that ensure support for families in meeting their responsibilities toward the child and promote the right of the child to have a relationship with both parents."<sup>248</sup>

The Guidelines have especially strong provisions for the protection of children under age three. They state that "[i]n accordance with the predominant opinion of experts, alternative care for young children, especially those under the age of three years, should be provided in family-based settings."<sup>249</sup> Standing alone, this language comes close to the requirements of the CRPD.

The Guidelines, unfortunately, are filled with exceptions and limitations to the obligation to eliminate institutions and place children with families. For children under age three, the Guidelines allow significant exceptions:

- 1. to prevent the separation of siblings;
- 2. when a placement is of an "emergency nature;" and
- 3. "for a predetermined and very limited duration, with planned family reintegration or other appropriate long-term solution as its outcome."<sup>250</sup>

The necessity of each of these three exceptions is questionable – they are all an extension of the "last resort" standard that assumes service systems are inadequate and will remain inadequate to meet the needs and best interests of children in these three circumstances. Their presence in the document may undermine the object and purpose of the basic right. And as with so many exceptions, there is a risk that they will swallow the rule.<sup>251</sup> To avoid the need for such

<sup>&</sup>lt;sup>247</sup> U.N. Guidelines, supra note 26, ¶ 23.

 $<sup>^{248}</sup>$  Id. ¶ 32.

 $<sup>^{249}</sup>$  Id. ¶ 22. The Guidelines allow an exception "to prevent the separation of siblings," which is problematic – unless it is also limited to very short-term placement "in cases where the placement is of an emergency nature or is for a predetermined and very limited duration, with planned family reintegration or other appropriate long-term care solution as its outcome." Id.

 $<sup>^{250}</sup>$  Id.

<sup>&</sup>lt;sup>251</sup> This is one reason why the drafters of the CRPD chose a different approach—protecting rights through "broad principles, not detailed exceptions . . . Allowing exceptions [to a human rights treaty can, in some contexts]

exceptions, governments could support kinship networks or create foster families ready to take children in situations of emergency. These models do exist. And foster families could also be created that would allow siblings to stay together. As with the "last resort" standard, this provision seems to be more of a guide to States on what to do when services are inadequate – rather than an affirmative statement of what the rights of children are and how services should be established.

There are larger and more serious limitations on the right to family within the Guidelines. First, the strict obligation to place children with a family ends at age three. This language does not reflect the findings of research that the dangers of growing up in group settings are also detrimental to older children. The research does not suggest a magic cut-off in a child's need for a family at the age of three. As a consequence of this – intentional or not – numerous international efforts to promote child care reform focus on children in the 0-3 age group – and neglect to make similar efforts for older children.<sup>252</sup>

Secondly, the Guidelines call for the elimination of large "institutions" but paradoxically call for the establishment of smaller "residential programs." The term "institutions" is never defined in the Guidelines, leaving it unclear as to exactly what is to be eliminated.<sup>253</sup> The critical language of the Guidelines states that:

> where large residential care facilities (institutions) remain, alternatives should be

undermine its very object and purpose as an instrument to ensure the equal rights of persons with disabilities." Melish, *supra* note 46, at 81.

<sup>&</sup>lt;sup>252</sup> See, e.g. UNICEF, COMPENDIUM OF PROMISING PRACTICES TO ENSURE THAT CHILDREN UNDER THE AGE OF THREE GROW UP IN A SAFE AND SUPPORTIVE FAMILY ENVIRONMENT, (2015). The background for this study explains that "[t]he adoption by the United Nations General Assembly in 2009 of the Guidelines for the Alternative Care of Children further clarified the priorities for such reform: for young children, those under the age of three, alternative care should be provided only in a family setting." *Id.* at 5.

<sup>&</sup>lt;sup>253</sup> Nigel Cantwell explains that only "large institutions . . . are to be targeted for deinstitutionalization, whereas residential care in general is recognized as a necessary component of the range of options to be foreseen to cater to the varied needs and circumstances of individual children, provided it is used only for positive reasons, i.e. when it is seen to correspond better to those needs and circumstances than would a family-based setting." Cantwell, *supra* note 21, at 268.

developed in the context of an overall deinstitutionalization strategy, with precise goals and objectives, which will allow for their progressive elimination.<sup>254</sup>

As referenced here, institutions are distinguished from other residential facilities because they are "large." This leaves open the gap that allows for the preservation of "small" institutions by simply renaming them as "residential" programs. The Guidelines call for *preservation* of what is called "residential care," stating that "residential care facilities and family-based care complement each other in meeting the needs of children..."<sup>255</sup> In practice, the Guidelines allow for institutions to be preserved under the name "residential care facilities" – as long as they are not "large" and they are made more humane:

To this end, States should establish care standards to ensure the quality and conditions that are conducive to the child's development, such as individualized and small-group care, and should evaluate existing facilities against these standards.<sup>256</sup>

Unlike the term "institution," the term "residential care" is defined in the Guidelines. The Guidelines distinguish between "family-based" care, which includes biological families, extended kinship care, and foster care. Residential care, in contrast, is defined as "care provided in any non-family-based group setting, such as places of safety for emergency care, transit centres in emergency situations, and all other short and long-term residential facilities, including group homes."<sup>257</sup> By allowing for "long-term residential facilities" the Guidelines undercut the requirement that any placement be for the shortest time possible.

By taking the position that residential programs can and should be part of the social service system, the

 $<sup>^{254}</sup>$  U.N. Guidelines, *supra* note 26, ¶23.

 $<sup>^{255}</sup>$  Id.

 $<sup>^{256}</sup>$  Id.

 $<sup>^{257}</sup>$  Id. ¶ 29(c) (iv). It is notable that what the Guidelines define as "residential care" would constitute an "institution" according to the U.N. Special Rapporteur on Disability, who stated that "[a]ny placement of children in a residential setting outside a family must be considered placement in an institution." 2019 Special Rapporteur on Disability Report, *supra* note 7, ¶19.

Guidelines encourage the establishment of social service systems in which children will be placed outside a family (including "short- and long-term care" facilities). The term "group home" can, under the Guidelines' definitions, refer to any long or short-term residential institution – so long as it is not "large."

By calling on governments to create standards for these residential institutions, the Guidelines anticipate that they can be made suitable for children. As research shows, however, the effort to make better group homes faces the same problems as earlier efforts to make better institutions. If there are not opportunities for children to form permanent emotional attachments, we now know that those efforts will fail.

The Guidelines contain important provisions that could, if fully enforced, provide protections to avoid improper placement of children in group homes. Paragraph 21 of the Guidelines, for example, states that residential care "should be limited to cases where such a setting is specifically appropriate, necessary, and constructive for the individual child concerned and his/her best interest."<sup>258</sup> If a society were to construct a social service system truly in the "best interest" of children, however, it would not create a situation in which a child would ever have to be placed in a group home as a first choice or last resort. If the CRC were to update General Comment No. 9 and recognize an enforceable, individual right to family for all children, detailed provisions of the Guidelines like those in paragraph 21 would take on greater meaning. To the extent that group care is ever used, it would only be a short-term placement for treatment or respite based on individual needs-and not as a system of group "homes" established to replace institutions or orphanages.

To understand the limitations of the Guidelines, it is necessary to see how they are applied in context. The "best interest" provision of paragraph 21 provides little protection to children with disabilities when social service systems are limited – e.g. in societies that lack family supports and community services for children with disabilities. UNICEF's 2015 regional study of countries in the CEE/CIS region, for example, found that foster programs for children with

 $^{258}$  Id.  $\P$  21.

disabilities "were almost non-existent."<sup>259</sup> On a recent investigation in Moldova and Romania, local authorities in both countries informed DRI investigators that many children with disabilities and significant support needs must be placed in institutions or group homes because disability supports are not part of their foster care systems. In these countries, children placed in group homes because of a disability are not placed there because it is in their "best interest." They are placed in group homes because of the failure of the service system to protect their basic rights. Observations by DRI investigators in the Republic of Georgia provide an example of the way key provisions of the Guidelines can be overlooked.

## V. REGIONAL EXPERIENCES AND OPPORTUNITIES

## A. Obligations of International Donors: Georgia as a Case Study

Recent experiences in the Republic of Georgia provide an opportunity to view the impact of the role of international donors and experts, as a major childcare reform program was led by UNICEF and funded extensively by the U.S. Agency for International Development (USAID) in that country. International donors should be particularly sensitive to the requirements of international law. The CRPD contains an innovative provision, not included in the CRC, which states that international donors share in the obligations to uphold the "purposes and objectives of the Convention."260 In General Comment No. 5, the CRPD Committee states that "[i]nvesting money obtained in the framework of international cooperation into development of new institutions or places of confinement or institutional models of care is not acceptable as it leads to segregation and isolation of persons with disabilities."261 To fulfill this requirement of international law, governments and donors must support programs that allow all children to enjoy their right to live and grow up in a family.

In practice, the U.N. Guidelines for the Alternative

<sup>&</sup>lt;sup>259</sup> UNICEF REGIONAL OFFICE FOR CEE/CIS, COMPENDIUM OF PROMISING PRACTICES TO ENSURE THAT CHILDREN UNDER THE AGE OF THREE GROW UP IN A SAFE AND SUPPORTIVE FAMILY ENVIRONMENT 13 (2015).

<sup>&</sup>lt;sup>260</sup> CRPD, *supra* note 5, art. 32(1).

<sup>&</sup>lt;sup>261</sup> General Comment No. 5, *supra* note 36, ¶ 97.

Care of Children, and not the U.N. CRPD, were the major tool for shaping UNICEF's efforts in Georgia. A highly regarded handbook on the implementation of the Guidelines, "Moving Forward: Implementing the Guidelines for the Alternative Care of Children," cites recent experience in Georgia as a "promising practice" in "ending the use of institutional care to strengthen the overall child protection system."262 Based on my own personal experiences in Georgia through the work of Disability Rights International (DRI), as published in DRI's report Left Behind: The Exclusion of Children and Adults with Disabilities from Reform and Rights Protection in the Republic of Georgia (2013), it is possible to come to very different conclusions about the Georgia experience. Indeed, lessons from Georgia provide a cautionary tale about the role of international donors – and about the ways international standards can and will be implemented.

Like many former republics of the Soviet Union, Georgia inherited an extensive orphanage system that included children with and without disabilities. After Georgia's war with Russia in 2008, the United States provided a massive aid package to the country. To its credit, the Republic of Georgia embarked on an ambitious program to close down its old orphanages. As described in "Implementing the Guidelines:"

The number of children living in all forms of large state run institutional care decreased from nearly 2,500 to under 250 between 2008 and 2012. Approximately 33% of all children from institutions have been reunited with their families. . . . Foster care has also expanded and strengthened. For those children who could not be reunited with family, the number of small group homes was increased from 15 to 45 in just two years, housing approximately 400 children.<sup>263</sup>

Georgia and UNICEF must be given significant credit for closing large institutions and reuniting many children with families.<sup>264</sup> Yet here, increasing the number of group

<sup>&</sup>lt;sup>262</sup> IMPLEMENTING THE GUIDELINES, *supra* note 27, at 45.

 $<sup>^{263}</sup>$  Id.

<sup>&</sup>lt;sup>264</sup> DISABILITY RIGHTS INTERNATIONAL, *supra* note 121, at 8.

homes to serve 400 children is lauded as a model rather than a step that fell short of family placement. This arrangement not only violates the requirements of the CRPD, it is not in the spirit of paragraph 21 of the U.N. Guidelines.

Despite this, it is easy to see Georgia as a nearly complete success in deinstitutionalization until the situation is examined more closely. In 2012 and 2013, DRI conducted an investigation to observe the status of reforms.<sup>265</sup> DRI found that children and adults with disabilities had been largely left out of reforms. Systems to support and protect families with disabilities had not been created, so it was impossible to include children with disabilities in most community programs. By 2013, when DRI published its report, there were still three institutions for children with disabilities – and funding for reform had come to an end. This included the Tbilisi Infants Home, a residential facility for infants who needed specialized medical treatment that extensively rehabilitated with domestic was and international funds.

The devastating human cost of leaving children with disabilities in residential facilities for "treatment" could be seen at the Tbilisi Infants Home, where infants with disabilities had been placed. DRI found that children at the home were denied essential medical care that was available in the country. Staff explained children were not treated because they were already damaged by hydrocephalus. One study at the time showed that the babies in this home experienced a 30% annual mortality rate.<sup>266</sup> Children with hydrocephalus were not even given pain medication. According to DRI's medical expert, these children were left to die in agony. Despite these failings, a large sign in the back yard indicated that the USAID had funded a playground at the institution – which most children would never be able to use.

DRI also found that the government of Georgia had no record of more than 1,000 children living in dozens of small institutions under religious and municipal authority. Local advocacy organizations later corroborated DRI findings, concluding that there is an entirely unregulated "shadow"

 $<sup>^{265}</sup>$  Id. The author made personal observations based on visits to institutions as well as interviews with government authorities, USAID, and UNICEF in July 2016.

 $<sup>^{266}</sup>$  Id.

system of small institutions in the country.<sup>267</sup> These children were never included in the governments' reform plans – and they were entirely overlooked by UNICEF (another reason to doubt UNICEF's global estimates of children in institutions is that they were off by 50% in Georgia). While the main focus of international funding was on the creation of community services for children, there was also a lack of attention to where children with disabilities would go when they grew up. USAID and the U.S. Army Corps of Engineers helped rebuild two institutions for adults with disabilities.

After DRI published its report, the Republic of Georgia immediately instituted new policies to ensure that children with disabilities received medical care. The U.S. Senate Committee on Appropriations included report language stating that reforms "resulted in the improper segregation of children and adults with disabilities."<sup>268</sup> As a result, USAID allocated additional funding to complete the reform process. USAID also gave DRI a grant to help develop advocacy groups run by people with disabilities and their families, and

<sup>268</sup> U.S. Senate, Department of State, Foreign Operations, and Related Programs Appropriations Bill, 2013, at 48, S. 3241, 112<sup>th</sup> Cong., 2d Sess. (2013), *available at* <a href="http://www.gpo.gov/fdsys/pkg/CRPT-112srpt172/pdf/CRPT-112srpt172.pdf">http://www.gpo.gov/fdsys/pkg/CRPT-112srpt172/pdf/CRPT-112srpt172.pdf</a>>. The Senate Report states that U.S. assistance to Georgia:

> [r]esulted in the improper segregation of children and adults with disabilities during a period in which the Government of Georgia adopted a policy of deinstitutionalization for children. The Committee directs USAID to rigorously implement its Disability Policy, which calls for community integration and full participation in society of people with disabilities, and ensure that USAID staff is properly trained. The Committee further directs USAID to work with Georgian officials, service providers, and disabled people's organizations to develop and implement a plan for the community integration of children and adults with disabilities who are in institutional settings.

<sup>&</sup>lt;sup>267</sup> These findings were later corroborated by the Georgian organization Partnership for Children, which found that there were 1,146 children living in 36 small residential institutions throughout Georgia. *See* PARTNERSHIP FOR CHILDREN, EQUAL TREATMENT TO THE SCHOOLS OF FAITH: FINAL REPORT OCTOBER 2015-2016 iii (2016) ("All of these services are unregulated and thus not covered by the statutory child-protection oversight and care standards. The services where these children reside in fact largely represents a shadow system of residential care services for children, where they are admitted without any assessment and decision of the mandated statutory guardianship and care authority. These children do not appear on the social services' records.") (report on file with author).

provided UNICEF with funding to help Georgia close down the Tbilisi Infants Home by creating community-based alternatives.

Despite this valuable progress, the government of Georgia continued to invest in rebuilding institutions for children with disabilities. Three institutions were consolidated to two by transferring children to rebuilt facilities. As of the last DRI visit in 2016, the Tbilisi Infants Home continued to accept new admissions. The UNICEF program to close the Tbilisi Infants Home consisted of a plan to replace it with group homes for the infants and young children.

The UNICEF program in Georgia led to improvements in care for many children. But the program does not actually comport with the Guidelines for Alternative Care, which state that "[i]n accordance with the predominant opinion of experts, alternative care for young children, especially those under the age of 3 years, should be provided in family-based settings."269 In Georgia, as in so many other places where group homes are presented as the norm for community integration, there was no pretense that placement in group homes is an individualized decision.<sup>270</sup> As is so often the case, once the option is created for a class of children to allow for the closure of large facilities, children must fit into the mold of the services offered. Group homes are not the exception to the rule – they are the rule. And once residential programs are allowed, as the Georgia experience shows, safeguards can be easily overlooked. Without the love and care of a family to look out for the child, abuse and neglect of the kind DRI documented in Georgia may be allowed to take place. Rather than being seen as a success story of the U.N. Guidelines, as indicated in "Moving Forward," the Georgia experiences the life-threatening dangers that take place when the right to live and grow up in a family are not strictly enforced.

<sup>&</sup>lt;sup>269</sup> U.N. Guidelines, *supra* note 26, ¶ 22.

 $<sup>^{270}</sup>$  The U.N. Guidelines specify that when residential placement is used, "care should be limited to cases where such a setting is specifically appropriate, necessary and constructive for the individual child concerned and in his/her best interest." *Id.* at ¶ 21.

## B. New Promise from the Inter-American System on Human Rights

right Framing a as a protection against discrimination may allow for that right to be adjudicable through the courts in legal systems that guarantee equal protection of the law but may lack the kind of very specific language on the right to family and community integration written into the CRPD. One example in this area can be seen in U.S. law in the case of *Olmstead vs. LC*.<sup>271</sup> In this case, the U.S. Supreme Court ruled that it is a form of discrimination to provide services only in the context of a segregated institution for a person who is capable of living in the community. Since the protection against discrimination under U.S. law derives from the Americans with Disabilities Act—and not from international law—the protections described by the U.S. Supreme Court are particular to U.S. law.<sup>272</sup>

DRI has brought a series of cases to the Inter-American Commission on Human Rights designed to demonstrate that the right to live in the community for persons with disabilities is enforceable through the courts.<sup>273</sup> If the right to community integration for people with disabilities is established as a protection against discrimination under international law, this could be valuable precedent to help establish a similar right to live and grow up with a family for all children.

DRI brought the first petition ever to the Inter-

 $<sup>^{271}</sup>$  Olmstead v. L.C., 527 U.S. 581 (1999) (holding the unjustified segregation of a person with a diagnosis of mental illness in an institution is a form of discrimination under Title II of the Americans with Disabilities Act (ADA)).

<sup>&</sup>lt;sup>272</sup> The CRPD arguably provides an even more robust protection of the right to live in the community, since that right applies to all persons with disabilities, and not just people considered by experts to be capable of living in the community. See generally Arlene Kanter, There's No Place Like Home: The Right to Live in the Community for People with Disabilities, under International Law and Domestic Laws of the United States and Israel, 45 ISRAEL L. REV. 181 (2012).

<sup>&</sup>lt;sup>273</sup> See Sofía Galván, Institutionalization and the Right of Persons with Disabilities to Live in the Community, within the Inter-American Human Rights System, HUM. RTS. BRIEF (Apr. 2018) (describing DRI's cases within the context of the jurisprudence of the inter-American human rights system), available at <http://hrbrief.org/2018/04/institutionalization-right-persons-disabilities-livecommunity-within-inter-american-human-rights-system/>.

American system demanding immediate protections against severe and irreversible abuses caused by placement of children and adults in the psychiatric facility in Paraguay.<sup>274</sup> The Inter-American Commission ordered "precautionary measures" on the part of Paraguay but did not specify exactly what the government's obligations were. That case resulted in a settlement, in which the government agreed to reduce the size of the facility and create a new system of communitybased services.<sup>275</sup>

In recent years, DRI has brought two cases specifically drawing on the anti-discrimination model used in *Olmstead* and seeking community integration as a form of protection against discrimination under the American Convention. The cases stem from institutions for people with disabilities detained at the Federico Mora psychiatric facility in Guatemala<sup>276</sup> and formerly detained at the Casa Esperanza institution in Mexico.<sup>277</sup> DRI has argued that the right to equal protection under the law, under the American Convention on Human Rights, should be interpreted using CRPD Article 19 as a guide. DRI has challenged the detention of children and adults with disabilities in Mexico and Guatemala because services are provided only in the segregated environment of the institution. DRI has argued that Mexico and Guatemala are under a positive obligation to provide services in the community so that people with disabilities can live as part of society.

The Inter-American Commission on Human Rights has not yet considered the merits of these claims. The Commission did, however, issue an encouraging report after

<sup>&</sup>lt;sup>274</sup> See Alison Hillman. Protecting Mental Disability Rights: A Success Story in the Inter-American Human Rights System, 3 HUM. RTS. BRIEF 1 (2005) (describing DRI's successful petition for precautionary measures and its impact). <sup>275</sup> Id. at 3.

<sup>&</sup>lt;sup>276</sup> See Priscila Rodriguez, Historic Recognition of the Right to Community Integration for Persons with Disabilities in the Inter-American Human Rights System, HUM. RTS. BRIEF (Apr. 2018) (describing DRI's Federico Mora case from Guatemala), available at <a href="http://hrbrief.org/2018/04/historic-recognition-right-">http://hrbrief.org/2018/04/historic-recognition-right-</a> community-integration-persons-disabilities-inter-american-human-rightssystem/>.

<sup>&</sup>lt;sup>277</sup> See Eric Rosenthal & Arlene Kanter, The Right of People with Disabilities to Asylum and Protection from Deportation on the Grounds of Prosecution or Torture Related to their Disability, HUM. RTS. BRIEF (Apr. 2018) (describing the Casa Esperanza case from Mexico), available at <a href="http://hrbrief.org/2018/04/right-">http://hrbrief.org/2018/04/right-</a> people-disabilities-asylum-protection-deportation-grounds-persecution-torturerelated-disability/>.

visiting the Federico Mora hospital in Guatemala. The report by the Inter-American Commission on Human Rights comes as close as anything under international law to the type of court-ordered deinstitutionalization created by the *Olmstead* decision in the United States:

> Because of the lack of community-based options for the patients of the Federico Mora Hospital to receive the necessary services and treatment outside the institution, the IACHR recommends that the State guarantee community living for these persons, by creating and establishing community-based services. For this purpose, the commission urges the State to adopt, among other ones, the following measures: a) expeditiously define a strategy for the deinstitutionalization of person with disabilities, with a timeline, sufficient resources and specific evaluation measures; b) ensure the participation of persons with disabilities, directly through and organizations in the representing them, design and implementation of said strategy, and c) allocate sufficient resources for the development of support services.<sup>278</sup>

This statement by the Inter-American Commission applies to an adult psychiatric institution and does not specifically address the concerns of children or a right to a family. It remains to be seen if the concerns of children will be addressed in the IACHR's forthcoming decision on the merits of DRI's case. It might be possible to obtain an even stronger order when it comes to the immediate and urgent need of a child to be reintegrated into the family. In demonstrating the link between the CRPD's right to community integration and the American Convention's protection against discrimination, however, this analysis is of great importance. As described below, this decision is also historic in its recognition of the right of stakeholders – including organizations of people with disabilities – to be involved in the design and implementation of reforms.

 $<sup>^{278}</sup>$  INTER-AMERICAN COMMISSION ON HUMAN RIGHTS, SITUATION OF HUMAN RIGHTS IN GUATEMALA ¶ 469 (2017), available at <a href="http://www.oas.org/en/iachr/reports/pdfs/Guatemala2017-en.pdf">http://www.oas.org/en/iachr/reports/pdfs/Guatemala2017-en.pdf</a>>.

## VI. RIGHT TO CHOICE AND PARTICIPATION

Article 12 of the CRC protects the right of children to be heard and to be represented in matters that affect them.<sup>279</sup> The CRC Committee has recognized that children and adolescents have evolving capacities, translating into a right to make increasingly important decisions about their lives as they approach adulthood.<sup>280</sup> Articles 7 and 12 of the CRPD recognize that children with disabilities have the same rights as other children, including the right to legal capacity.

The recognition of a child's right to make choices about his or her life inevitably raises the question as to whether a child or adolescent should have the right to *choose* to live in a residential program or group home rather than accept placement in a family or foster family. Some international development experts have suggested that group home placement "may" be acceptable for "some adolescents living on the street [who] are not willing or able to return to their family of origin or live in a substitute family."<sup>281</sup>

On a matter as consequential as choosing to live without a family – and making a choice shown by extensive scientific to be inherently detrimental – there are significant reasons to be careful about leaving this decision to a child or adolescent. In addition to the inherent dangers of group care, children who grow up without a family often face the prospect of government support coming to an end when they reach adulthood. In contrast, children who have formed ties

<sup>&</sup>lt;sup>279</sup> See generally E. Kay M. Tisdall, Children and Young People's Participation: A Critical Consideration of Article 12, in ROUTLEDGE INTERNATIONAL HANDBOOK OF CHILDREN'S RIGHTS STUDIES 185 (Wouter Vandenhole et al., eds. 2015) (describing the obligations and experiences of engaging children and youth in policies that affect them).

<sup>&</sup>lt;sup>280</sup> Committee on the Rights of the Child, General Comment No. 20: Implementation of the rights of the child during adolescence ¶¶ 18-19, U.N. Doc. CRC/C/GC/20 (2016) [hereinafter CRC General Comment No. 20]. See also GERISON LANDSOWN, THE EVOLVING CAPACITIES OF THE CHILD (2005) (summarizing legal standards, research, and experience on the implementation of the right to legal capacity for children), available at <https://www.unicefirc.org/publications/pdf/evolving-eng.pdf>; Committee on the Rights of Persons with Disabilities, General Comment No. 1: Article 12: Equal Recognition Before the Law ¶ 4, U.N. Doc. CRPD/C/GC/1 (2014) available at <https://documents-ddsny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement; U.N. Secretary-General>.

<sup>&</sup>lt;sup>281</sup> WILLIAMSON & GREENBERG, *supra* note 90, at 3.

with families can usually count on continued support even when no government aid is available. The transition to adulthood outside a family is especially difficult for children with disabilities who have continued support needs. In countries that do not have adequate supports for adults with disabilities, many children with disabilities who grow up in group homes face the prospect of returning to institutions as adults.

As an investigator who has visited group homes and other residential institutions around the world, one of the saddest situations I encounter are the many children who have had the experience of living with a family or foster family and are forced into group care. These are the children who have had a taste of family life and know what they are missing, often pleading with U.S. to return to a family. Furthermore, there is extensive evidence that if parents had meaningful choice they would not give up their children to institutions or residential care. Parents do not willingly give up their children or place them in institutions the world over – and would go to great lengths to keep their children if given the opportunity to do so.<sup>282</sup>

While the CRC and CRPD recognize the right of the child to make choices and be heard about their lives, there are many reasons to be skeptical about whether true choice is actually available. When a child is offered residential care and no good, safe, supportive family options are available, they are not making a true choice. As described by the CRPD Committee in General Comment No. 5:

Often, persons with disabilities cannot exercise choice because there is a lack of options to choose from. This is the case, for instance . . . where support is unavailable outside of institutions, where housing in inaccessible or support is not provided in the community, and where support is provided only within specified forms of residence such as group homes or institutions.<sup>283</sup>

In societies that offer no supportive foster care for children with disabilities, children unable to stay with their biological family cannot make a meaningful choice to live in

<sup>&</sup>lt;sup>282</sup> See notes 69-78 supra and accompanying text.

<sup>&</sup>lt;sup>283</sup> General Comment No. 5, *supra* note 36, ¶ 25.

residential care. Thus, if a child has grown up in an institution or in residential care and has never experienced family life, he or she cannot be expected to truly understand the implications of this decision.

The CRC Committee has recognized this evolving capacity as children enter their adolescence as taking on greater importance "the more a child knows and understands" to the point when decisions must be made in "an exchange on an equal footing."<sup>284</sup> In the CRC framework, an understanding of evolving capacity does not just rely on a child's age but on his or her individual experiences and abilities. That said, the CRC recognized that "the right to exercise increasing level of responsibility does not obviate States' obligation to guarantee protection."<sup>285</sup> The CRC Committee says that in establishing a "balance between respect for the evolving capacities of adolescents and appropriate levels of protection, consideration should be given to the range of factors affecting decision-making, including the level of risk involved, the potential for exploitation, understanding of adolescent development, recognition that competence and understanding do not necessarily develop equally across all fields at the same pace and recognition of individual experience and capacity."286 According to the CRC, evolving capacities must be weighed against the known dangers of institutions.<sup>287</sup>

The framework for protection of choice under the CRPD is similar, but it shifts the focus away from the capacity of the individual and toward the universal need for support:

The existence of adequate and age-sensitive support services for girls and boys with disabilities is of vital importance for the equal enjoyment of their human rights (art.7)

<sup>&</sup>lt;sup>284</sup> CRC General Comment No. 20, *supra* note 280, ¶ 18.

<sup>&</sup>lt;sup>285</sup> *Id.* ¶ 19.

<sup>&</sup>lt;sup>286</sup> *Id.* ¶ 20.

 $<sup>^{287}</sup>$  Id. ¶52 (finding that this weighing includes "significant evidence of poor outcomes for adolescents in large long-term institutions, as well as other forms of alternative care, such as fostering and small group care, albeit to a much lesser degree. . . . Adolescents in alternative care are commonly required to leave once they reach 16-18 years of age and are particularly vulnerable to sexual abuse and exploitation, trafficking and violence as they lack support system or protection and have been afforded no opportunities to acquire the skills and capacities to protect themselves.").

respecting the evolving capacities of children with disabilities and supporting them in having a say in choices that have an impact on them is critical. It is also important to provide support, information and guidance to families (art.23) to prevent institutionalization of children with disabilities . . . .<sup>"288</sup>

Article 19 of the CRPD protects the right to live in the community "with choices equal to others," but the CRPD Committee has specified in General Comment No. 5 that this choice can only be made in the community. General Comment No. 5 states that "all rights should be enjoyed in the community where a person chooses to live and in which alone the free and full development of one's personality can be fulfilled."<sup>289</sup> If an adult cannot exercise choice within an institution, it is hard to imagine a child doing so. Without the experience of living in a truly supportive family, the choice of a child to live in an institution or any form of residential care should not be considered a free exercise of his or her rights.

While there is every reason to be skeptical about the choice of a child or adolescent to give up his or her right to a family, it is important to recognize the rights of both children and families to advocate for the right to keep families together – and to supportive services that would make this possible. The CRPD Committee calls on States Parties to "empower family members to support the family members with disabilities to realize their right to live independently and be included in the community."<sup>290</sup>

The CRPD also requires participation of parents as stakeholders not only in individual decisions about care about the broader political and policy decisions about the creation of support systems in the community. One of the core principles of the disability rights field is that stakeholders – people with disabilities "through their representative organizations" – can play a role in "transforming support services and communities and in the design and implementation of deinstitutionalization strategies."<sup>291</sup>

Article 4(3) of the CRPD recognizes that people with

<sup>&</sup>lt;sup>288</sup> General Comment No. 5, *supra* note 36, ¶ 75.

<sup>&</sup>lt;sup>289</sup> *Id.* ¶ 69.

 $<sup>^{290}</sup>$  Id. ¶ 55.

<sup>&</sup>lt;sup>291</sup> Id. ¶ 97(i).

disabilities have the right to participate in matters of policy and program on matters that affect them. The structure of social service systems that would break up families and place children in group homes or other residential care institutions have impacts on the rights of both children and adults with disabilities. These individuals and communities have a right to a say in their future.

The obligation to enforce the right of children to grow up in a family falls on governments. But experience shows that advocacy by stakeholders can be critical to holding governments accountable and keeping up sustained pressure on them to meet the requirements of international law. If government authorities and international donors listened to the voices of children placed in group homes and institutions, perhaps it would not be necessary to have or cite these numerous international standards and guidelines.

These experiences suggest a close and powerful alliance that can be formed among children's rights activists and disability activists. These groups share a common interest in establishing strong protections and support systems for families to ensure that no child is placed in an institution.

## VII. BUILDING ON THE INDIVISIBILITY AND THE INTERDEPENDENCE OF RIGHTS

As this paper has described, the CRC and CRPD, the General Comments, and the U.N. Guidelines can be understood and implemented within two parallel legal systems – almost as if they existed in parallel universes. But they are not parallel universes. If the findings of scientific research tell U.S. anything, children do not need to be seen or labeled with a disability to feel and experience the emotional impact of institutions, residential homes, or any form of group care. From babies to adolescents, children raised without a family can and will experience the trauma of family separation and the psychological damage of growing up without a family, as well as developmental delays that arise from emotional neglect and lack of stimulation in a group setting.<sup>292</sup> Segregation from society is itself damaging and contributes to disability. The children

<sup>&</sup>lt;sup>292</sup> Dozier et al., *supra* note 43, at 222.

protected by the CRC and the CRPD growing up without a family are the same children. The institutions, residential care, and group homes that keep them from growing up with families are the barriers that "hinder their effective participation in society on an equal basis with others" as CRC General Comment No. 9 and the CRPD are intended to protect against.<sup>293</sup>

These overlapping populations and overlapping rights are inevitable, and international law has developed over the last twenty years to recognize that all rights enforcement will be more effective when these systems are seen as a common whole. These should not be warring legal systems. Protecting families is a core purpose of the CRC as much as protecting community and family integration is a part of the CRPD. Both legal systems will be stronger if implemented together.

At the World Conference on Human Rights in Vienna, the international community reaffirmed that "[a]ll human rights are universal, indivisible and interdependent and inter-related."<sup>294</sup> Thus, to the extent possible, the U.N. human rights conventions should be read in a manner that is consistent and mutually complementary. Instead of later human rights conventions supplanting earlier ones, the Vienna Convention on the Law of Treaties calls for the interpretations of each convention to be "taken into account" in the interpretation of the others.<sup>295</sup> The Vienna Convention makes clear that the authority of any particular treaty interpretation must be understood within the "context" in which it is to be implemented, as well as "subsequent practice" of states parties.<sup>296</sup> Interpretations of treaties evolve over time, as long as they advance the original "object and purpose" of those treaties.<sup>297</sup>

The lessons learned from experience, findings from scientific research, and new legal standards established in the CRPD should not be seen as trumping or taking precedence over the rights established in the CRC—they should be seen as making those rights more effective. Under the Vienna Convention, the language of treaties must be

 $<sup>^{293}</sup>$  CRPD, supra note 5, art. 1; CRC General Comment No. 9, supra note 16,  $\P$  7.

 $<sup>^{294}</sup>$  World Conference on Human Rights, Vienna Declaration and Programme of Action  $\P$  5, U.N. Doc. A/CONF.157/23 (1993).

<sup>&</sup>lt;sup>295</sup> VCLT, *supra* note 11, art. 31(3)(c).

<sup>&</sup>lt;sup>296</sup> Id. arts. 32(2)-(3).

<sup>&</sup>lt;sup>297</sup> Id. art. 31(1).

interpreted "in good faith in accordance with the ordinary meaning to be given to the terms of the treatment in their context and in light of its object and purpose."<sup>298</sup> Human rights treaties have been recognized as "*living instruments*, the interpretation of which must evolve over time in view of existing circumstances."<sup>299</sup> The CRC is clearly intended to protect the "best interests" of the child, and research now shows that the best interest of the child is best protected in the context of a family – not in "family-like" group care. If research tells U.S. that there are no "suitable institutions" for children, then the language of CRC Article 20 leaves children with the option of family and foster family – exactly as represented in the language of CRPD Article 23(5).

Perhaps the most profound insight of the CRPD is reflected in the social model of disability – that it is not the individual who needs to be fixed to meet the standards of society, but the society that must be made accessible to all children. When the "last resort" standard is used, the child loses the opportunity to live and grow up with a family because of a social service system's lack of supports in the community. Inadequacies of the system should not be the basis for denying children's fundamental rights. And this principle applies to both children with and without disabilities. When barriers are removed and society is broadly welcoming and supportive of all children growing up with families, all children benefit.

Scholars of international disability law, such as Professor Arlene Kanter, have observed that the CRPD has universal implications beyond the population it was drafted to protect.<sup>300</sup> In recent years, the U.N. Special Rapporteur on Disability, Catalina Devandas, has affirmatively taken this approach with regard to the rights of people with disabilities, children, and elders. In her 2016 report, she endorsed the idea that this has implications for the interpretation of other human rights instruments:

> The Convention challenges traditional approaches to care and has the potential to redress the legacy of disempowerment and

 $<sup>^{298}</sup>$  Id.

<sup>&</sup>lt;sup>299</sup> The Right to Information on Consular Assistance in the Framework of the Grantees of Due Process of Law, Advisory Opinion OC-16/99, Inter-Am. Ct. H.R., Oct. 1, 1999 (Ser. A) No. 16, ¶ 114 (emphasis added).

<sup>&</sup>lt;sup>300</sup> KANTER, *supra* note 47, at 5.

paternalism. Furthermore, the notion of support in the Convention also has the potential to override traditional understanding of care and assistance for other groups, *such as older persons and children*. The Convention restores the importance of the "human being" in the human rights discourse by emphasizing the individual and social aspects of the human existence. These innovations can and should be incorporated into the implementation of all existing human rights instruments.<sup>301</sup>

In 2017, Special Rapporteur Devandas returned to this theme when she stated that "the Convention has expanded the understanding of the right to equal protection before the law in the international human rights system for people with disabilities and for other groups."<sup>302</sup>

## VIII. CONCLUSION

This paper has demonstrated that the CRPD creates protections for the right to family, based on a social model of disability, that provide stronger and more effective protections than standards used to interpret and implement the CRC, such as General Comment No. 9 and the U.N. Guidelines for Alternative Care. These protections are consistent with the findings of research and experience since the CRC was drafted thirty years ago showing that group residential care is inherently dangerous for children with and without disabilities. Since the purpose of the CRC is also meant to help all children live and grow up with a family, the CRC Committee should review and strengthen General Comment No. 9. Article 41 of the CRC requires that newer international standards creating stronger protections for children be recognized, and the new CRPD standard can be used as a guide to the evolution of international law. As provided for by CRPD Article 23(5), children unable to stay with immediate family should still be cared for in a wider family or family setting. CRPD General Comment No. 5 now makes clear that residential care and group homes are not a

 $<sup>^{301}</sup>$  Catalina Devandas Report of the Special Rapporteur on the Rights of Persons with Disabilities  $\P41,$  U.N. Doc. A/HRC/34/58 (2016) (emphasis added).

 $<sup>^{302}</sup>$  Catalina Devandas, Report of the Special Rapporteur on the Rights of Persons with Disabilities  $\P$  21, U.N. Doc. A/HRC/37/56 (2017) (emphasis added).

"family setting"—and they are no substitute for the right of every child to live and grow up with a family.

The U.N. Guidelines include valuable language on the protection of families and on the need to plan for the elimination of institutions, and this language should be recognized and implemented. As a non-binding guideline for government action to protect children, however, the U.N. Guidelines must conform to the requirements of binding conventions – including the CRC and the CRPD. Language calling on governments to maintain "residential" homes is clearly not consistent with the requirements of the CRPD – and should not be seen as meeting the requirements of a new General Comment under the CRC.

The social model of disability, shifting the obligation to adapt from the individual to the society, provides insight into the limitations of such principles, and a legal framework for the effective protection of the right of all children to live and grow up with a family. This legal framework does not allow for the denial of rights "as a last resort" because social service and child protection systems are inadequate. It is society's obligation to adapt its social care system to allow *all* children, with or without a disability, to enjoy their right to live and grow up with a family. It should no longer be possible to say that any child is too sick, too impaired, too behaviorally compromised, or too "disabled" to live and grow up with a family.

The vast majority of children now placed in institutions, residential care, or group homes have parents who have never been given the support, opportunities or accommodations they need to keep their children. The CRPD's social model of disability opens an avenue for protection against discrimination that can help children and parents *perceived* as disabled, unhealthy, inadequate, or unable stay together. Modern practice in social services now shows that support programs can help most families stay together to create a nurturing and loving environment for children. Instead of taking away the right of children to grow up with a family, international law now requires that families be given a chance to succeed and thrive through support and protection.

There are enormous challenges to implement these rights in social service systems that do not have adequate supports for families, support for extended kinship networks to keep children in the family, or foster care programs that will allow children with disabilities to live in the family. But the argument that these children will otherwise be dumped onto the streets must not be used to deny children's' rights. When social service and child protection systems are inadequate, governments must take whatever action needed to mitigate damage to children and choose the least dangerous option for them. But the core right to live and grow up with a family never needs to be suspended and must always serve as the guide and the goal of future reform.

Experience shows that, if these principles are compromised from the outset, true rights protection and effective reform can never be expected to happen. We live in a world in which there are never enough resources for the most at-risk populations, and mustering the political will to protect the rights of children and people with disabilities is always a challenge. Well-meaning reformers will always be under pressure to make compromises, to accept less than what children optimally need in order to serve the greatest number the most quickly. International charities and development organizations often assume that, in developing countries, social services cannot live up to the standards they would expect and demand to serve their own children at home. Governments may be hesitant to make changes that they believe will drive up costs. Service providers and entrenched interests may be vested in the status quo and may oppose change. For children with disabilities who languish in institutions or residential care with little support, any improvement of care will likely increase cost. Despite all of this, good care in a family environment is less costly than in an institution, residential care, or group home. When the damage caused to children is factored-in over the long term, the cost to the child and to society is likely to be much less when rights are fully enforced and children grow up with families.

Rather than viewing the CRC and CRPD as conflicting or inhabiting parallel universes, the right to a family can be seen as a unifying principle. The legal protections established in the CRPD are a more effective way to meet the goals of the CRC's drafters, who recognized that children "should grow up in a family environment of happiness, love and understanding."<sup>303</sup> Happiness, love, and understanding cannot be mandated by international law – but full protection of the right to family can. Full enforcement of the right to family under the CRC requires looking to a sister convention – the CRPD.

<sup>&</sup>lt;sup>303</sup> CRC, *supra* note 4, pmbl.

As the CRC approaches its thirtieth anniversary, some children's rights experts have looked back at experience and have called for a return to first principles. All too often, they have observed, "the CRC is still considered as a kind of (soft) 'declaration of love.' Therefore, it should be repeated that the CRC is a Convention and Conventions are so-called 'hard law,' in other words legally binding...."<sup>304</sup> For children, it is not enough to adopt policies and programs that lead toward the protection of families. Children grow up quickly. They have no time to lose.

<sup>&</sup>lt;sup>304</sup> Verhellen, *supra* note 223, at 52.