

**Position paper:
The right to live and grow up in a family for *all* children**

**Children with and without disabilities
have the right and the need
to grow up in families
not in institutions, residential care, or group homes**

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European Network for Independent Living
Validity
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Executive Summary – Throughout the world, children with disabilities are separated from families due to stigma, discrimination, and economic marginalization. Children with disabilities are more at risk of being placed in institutions than other children, and they are often left out of deinstitutionalization and community programs. Without community-based supports to help families keep their children with disabilities, children in many countries are increasingly placed in a new generation of smaller institutions being created to replace orphanages – often with international funds. These may be called “residential” programs, family-like residences, or group homes, but they leave children without the opportunity to grow up with the love and permanent bonds they can only form in a family.

International law establishes that *all* children – including children with disabilities – have the need and right to live and grow up in a family.

Article 19 of the CRPD protects the right of *all* people with disabilities to live in the community. In General Comment No. 5, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) unequivocally states that “[f]or children, the core of the right to be included in the community entails a right to grow up in a family.”¹ The CRPD Committee goes on to explain that:

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.²

The CRPD, as interpreted by General Comment No. 5, provides stronger protections than does the Convention on the Rights of the Child (CRC) and the guidelines for its

¹ U.N. Secretary-General, *General Comment No. 5 (2017) on living independently and being included in the community*, U.N. Doc. CRPD/C/GC/5 (Oct. 27, 2017), para. 37. [hereinafter General Comment No. 5] (emphasis added).

² *Id.*, para. 16(c).

implementation.³ The UN Guidelines for Alternative Care of Children call for the elimination of large institutions but still allow governments to retain smaller “residential care facilities” for children above three years old. Extensive new research now shows that children of *all ages* need to grow up with a family – and face dangers in any form of group care. The right to grow up with a family must be recognized and implemented for all children of all ages.

Anything other than a family constitutes institutional care and does not comply with human rights law. Thus, an “institution” should be understood as any residence other than a family. A family may not necessarily be the immediate biological family, but could include extended family, kinship care, foster care, substitute family care, or any family environment in which the child can establish stable emotional bonds. Throughout the world, there are successful models that demonstrate that all children – regardless of disability – can live and grow up with a family.

Limitations of the Convention on the Rights of the Child

The right of a child to a family in international law is grounded in a widely accepted principle, stated in the preamble of the CRC, which recognizes that children “should grow up in a family environment.” The CRC preamble affirms that family is the “fundamental group of society and the natural environment for the growth and well-being of all its members” which should be afforded “protection and assistance...”. Inter-related articles in the CRC protect the child’s right to grow up with a family.⁴

Despite recognizing the importance of family, however, Article 20 of the CRC leaves the door open to placement in “suitable institutions.” CRC Article 23(1) recognizes the right of children with disabilities to “active participation in the community” but does not specifically say that this means placement in a family. Smaller residences may be physically located in the community, but they can still deprive children of the opportunity to live in a family. CRC Article 23(3) creates a right to education, health care, and social services that allow the “fullest possible” integration of the child. Valuable as this is, this requirement allows for the interpretation that family integration of some children is not possible.

Over the thirty years since the CRC was adopted, there have been great advances in knowledge about human development. Corresponding to these developments,

³ See discussion below. Article 20 of the CRC allows children to be placed in “suitable institutions.” As stated by Dr. Dainius Puras on behalf of the European division of UN High Commission on Human Rights (UNHCHR), “[t]he CRC was drafted during the 1980s, when the issue of institutionalization was not perceived as one of the most serious concerns....*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...*” United Nations Office of the High Commissioner on Human Rights, Regional Office for Europe, *The Rights of Vulnerable Children Under the Age of Three: Ending their Placement in Institutional Care*, 11 (2011).

⁴ Article 7(1) of the CRC establishes that the child has the “right to know and be cared for by his or her parents.” Under Article 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.”

international standards and law have evolved over time, culminating in the adoption and entry into force of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2008. Between the time the CRC and CRPD entered into force, various international standards were established to call on governments to reform social service systems to protect children in out-of-home care.⁵ Most of these reforms were guided by standards drafted *before* the CRPD entered into force. In 2006, the UN Committee on the Rights of the Child adopted General Comment No. 9 to define the application of the CRC to children with disabilities.⁶ General Comment No. 9 was progressive at the time it was adopted because it limited any placement in an institution to the “last resort.” But General Comment No. 9 was not informed by the stronger protections established by the CRPD.

In practice, the “last resort” standard does not provide as much protection for children with disabilities as for other children. In countries where there are no services or support systems to help families keep their children with disabilities, the institution will always be the last resort. And in countries that have developed smaller “family-like” residences or group homes, this system effectively becomes a second-class system of services and the only option for large numbers of children with disabilities.

New protections under the CRPD – for children with and without disabilities

The CRPD establishes important protections implications for all children. These protections derive from Article 23 (“respect for home and the family”) and Article 19, which recognizes that 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.”⁷ Article 19 is universal in its commitment to integration as it applies to *all* people with disabilities – no matter the type or severity of their disability.⁸

CRPD Article 23(5) states that “where the immediate family is unable to care for a child with disabilities” the state must provide care “within the wider family, and failing that, within the community in a family setting.” This article does not explicitly prohibit placement in an institution, but it also does not allow for any option outside a “family setting.” In this regard, CRPD Article 23(5) provides stronger protections than CRC Article 20.

While the CRC recognizes a right to the “fullest possible” social integration for children with

⁵ 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, Protecting Children against Torture in Detention* p. 303, 312-313 (2017) (describing the obligations under the CRC, the CRPD and the Convention Against Torture to avoid the unnecessary confinement of children in institutions and to create services and supports for families to avoid new placements).

⁶ U.N. Secretary-General, *General Comment No. 9 (2006): The rights of children with disabilities*, U.N. Doc. CRC/C/GC/9, para 47 (Feb. 27, 2007) [hereinafter “General Comment No. 9”].

⁷ Commissioner for Human Rights of the Council of Europe, *The Right of People with Disabilities to live Independently and be Included in the Community*, Commissioner, (2012) at 4.

⁸ *General Comment No.5* at paras 20-21.

disabilities, the CRC implicitly assumes that full integration is not possible for some children. The CRPD takes a different approach. Instead of determining whether a child is too disabled to live in society as part of a family, CRPD Article 19 requires society to become accessible by providing the support necessary to allow that child to live and grow up in a family.

When parents are placed in institutions, children lose their family and are often left to grow up in institutions as well. By protecting the rights of parents with disabilities to live as full members of society, the CRPD helps their children (with and without disabilities) avoid placement in institutions.

The language of CRPD General Comment No. 5 refers to “children” and not just children with disabilities. This is consistent with CRPD 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.”⁹ CRPD Article 23(4) protects “children” (and not just “children with disabilities”) from family separation if their parents are disabled or are wrongly perceived to be unable to keep their children. Instead of breaking up families, the CRPD requires support to families. By protecting 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.

Legal commentators have observed that the paradigm shift brought about by the CRPD expands rights for all people, benefiting society as a whole and protecting other groups also excluded by these barriers.¹⁰ UN Special Rapporteur on Disability Catalina Devandas follows this approach by stating that:

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.¹¹

Both the CRC and the CRPD protect families, but the CRPD provides a stronger and more unequivocal protection. The right of children to live and grow up in the family, now recognized under the CRPD, can be used to reinterpret the CRC to protect the right of *all* children to live and grow up in a family.

All children can and must be integrated into families

If the right to live with a family were fully enforced, it would not be necessary to place any

⁹ Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, UN GAOR, 61st Sess. Supp. No. 49, UN Doc. A/RES/61/106, Annex II, at 65 (13 December 2006)[entered into force May 3, 2008].

¹⁰ Arlene Kanter, *THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW* 49 (2015).

¹¹ U.N. Catalina Devandas, *Report of the Special Rapporteur on the rights of persons with disabilities*, U.N. Doc A/HRC/34/58, para.41 (Dec 20, 2016).

child in an orphanage or institution of any size. If a child does not have parents or cannot live with them, alternatives can be made available to ensure that a child can live and grow up with a family – including kinship care, substitute family care, or foster care. It was once believed that some children with disabilities would have to be placed in some form of residential care. Experience now shows that, with appropriate support, children with “every kind and severity of impairment [are] currently living successfully with a family.”¹²

In practice, the vast majority of children placed in orphanages are not orphans. Estimates vary by country, but some 80-98% of children placed in orphanages have at least one living parent.¹³ Children are usually placed in institutions because of poverty or disability.¹⁴ When children receive the protection and support they need to live and grow up with a family, it is possible to reduce and eliminate orphanages and other institutions for children.¹⁵

Developing countries may lack trained professionals and have competing demands for funding. As it happens, the most progressive solutions for family inclusion do not rely on the most highly trained professionals. Best practices for inclusion build upon “natural supports” already in the community – family, friends, and existing social networks.¹⁶ Models have been established showing that children with the most serious behavioral issues and multiple disabilities can be supported to live with families.¹⁷ As one expert observed, “[w]hile treatment can occur in a family, family cannot occur in a facility.”¹⁸

As with the population of children placed in orphanages and larger institutions, the vast majority of children in small residences and group homes also have parents. If those parents are abusive or truly unable to take care of their children, the CRC rightly requires that children be removed from their parents. But if parents could keep their children with support, it is a form of disability discrimination to improperly label them as “unfit” parents and take their children.

¹² Nancy Rosenau, *Do We Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities*, University of Minnesota Institute on Community, Integration Policy Research Brief 7 (2000).

¹³ See, e.g. Lumos, *In our Lifetime: How Donors Can End the Institutionalization of Children*, 12 (Sept, 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*, *Every Child*, 1 (2005) (estimating the number of children with parents as high as 99%).

¹⁴ Faith in Action Initiative, *Children, Orphanages, and Families: A Summary of Research to Help Guide Faith-Based Action* p. 6 (2014); UNICEF, *Children in Institutions: The Beginning of the End?* p. v. (2003).

¹⁵ Raymond Lemay, *Deinstitutionalization of People with Developmental Disabilities: A Review of the Literature*, 28 *CANADIAN J. COMMUNITY MENTAL HEALTH* 181-194 (2009).

¹⁶ Rosenau, *supra* note 12; Alicia DeLashmutt, *Homes, Not Housing*, 41 *TASH Connections* 3 (Fall 2015), posted at <https://tash.org/wp-content/uploads/2016/05/Connections-v41n3-DeLashmutt.pdf>.

¹⁷ John C. Berens and 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, Carmen Irby, Sandra Withers, Susan Dorsey, Jingyun Li, Malik Rettiganti, *Home Visiting and Health of Preterm Infants*, 56 *CLINICAL PEDIATRICS* 828-837 (2017).

¹⁸ *Id.* at 4.

Dangers of small institutions and group homes

Group homes and “family-like” residences are like institutions rather than families because, among other reasons, staff work in shifts and it is impossible for children to establish the permanent attachments with adults they need.¹⁹ Based on a review of research literature in child welfare, an international group of professionals issued a consensus statement:

...group settings should not be used as living arrangements, because of their ***inherently detrimental*** effects on the healthy development of children, regardless of age.²⁰

The consensus includes TASH, an international organization of people with disabilities, families, and developmental disability professionals, taking the position that “all children, regardless of disability, belong with families and need enduring relationships with adults.”²¹ The American Academy of Pediatrics has endorsed a call to “reduce to zero the number of children aged 17 and younger living in congregate care...”²² Inclusion International, the leading international organization of people with intellectual disabilities and their families, has called for governments and donors to “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.”²³

The UN Guidelines for Alternative Care, adopted by the United Nations as a guide to the implementation of the CRC, takes a strong stand on the need to protect families and 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.”²⁴ The Guidelines take an especially strong stand to protect all children under the age of three by requiring that they be placed in a family:

The Guidelines provide that “[i]n accordance with the predominant opinion

¹⁹Mary Dozier, Joan Kaufman, Roger Kobak, Thomos G. O’Connor, Abraham Sagi-Schwartz, Stephen Scott, Carole Shauffer, Judith Smetana, Marinus H. van IJendoorn, and Charles Zeanah, *Consensus Statement on Group Care for Children and Adolescents: A Statement of Policy of the American Orthopsychiatric Association*, 84 *American Journal of Orthopsychiatry* 219, 220 (2014). Another study compared children who attained permanence in a family setting to 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. Katie K. Lockwood, Susan Friedman, and Cindy W. Christian, *Permanency and the Foster Care System*, 45 *CURRENT PROBLEMS IN ADOLESCENT HEALTH CARE* 306-15 (2015).

²⁰ Dozier (2014), *supra* note 19, at 220 (emphasis added).

²¹ TASH, “Resolution on Life in the Community” (July 2000) posted at <https://tash.org/about/resolutions/tash-resolution-life-community/> (last visited June 13, 2018).

²² American Academy of Pediatrics, *Clinical Report: Out-of-Home Placement for Children and Adolescents with Disabilities* 134 *PEDIATRICS* 836, 837 (2014).

²³ Inclusion International, *INCLUSIVE COMMUNITIES = STRONGER COMMUNITIES* 120 (October 2012).

²⁴ Guidelines for the Alternative Care of Children, GA Res 64/142, para. 32 (Feb. 24, 2010) [hereinafter “Guidelines for Alternative Care” or “the Guidelines”].

of experts, alternative care for young children, especially those under the age of three years, should be provided in family-based settings.²⁵

While early research focused on the dangers for children in the 0-3 age range, it is now understood that congregate settings are detrimental to older children as well.²⁶ “Children of *all ages* need long-term, supportive parenting relationships – permanence, in child welfare parlance.”²⁷ Based on the growing body of research showing that group care is detrimental to children of all ages, the protections for the youngest children established under the UN Guidelines for Alternative Care must be extended to all children.

Need to bring UN standards into compliance with the CRPD

The CRPD is the newest and most comprehensive international human rights convention, and it most fully reflects the findings of years of experience and research showing that all children – including all children with disabilities – can live with a family. International standards on children drafted or adopted by the United Nations *before* the CRPD must now be updated to reflect the right of all children to grow up with a family. The most important priority is an update of General Comment No. 9 of the UN Committee on the Rights of the Child regarding children with disabilities.

Despite the inherent dangers of large and small institutions, CRC’s General Comment No. 9 includes language that can be used by governments to justify investments in institutions. Instead of calling for elimination of institutions, General Comment No. 9 calls for their “transformation” into more humane residences – where children are still left to live without a family. These recommendations conflict with CRPD General Comment No. 5.

Instead of accepting that some children can be placed in institutions as a last resort, the CRPD Committee has suggested governments should stop any placement of children in institutions. In September 2016, the Committee asked Guatemala to “abolish institutionalization” of children.²⁸ This Comment appears to endorse a moratorium on new placements in institutions. The Committee’s statement has broad implications as it refers to all “children’ and not “children with disabilities.”

An update to CRC General Comment No. 9 would remedy certain limitation of the UN Guidelines for Alternative Care. Despite their great value, the Guidelines unfortunately include provisions that do not fully comply with the CRPD. The Guidelines allow for children

²⁵ *Id.*, para. 22.

²⁶ *Id.*, para 22.

²⁷ 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).

²⁸ “Abolish the institutionalization of children of any age” UN Committee on the Rights of Persons with Disabilities, *Concluding Observations of the Committee on the Rights of Persons with Disabilities on the Initial Report of Guatemala*, UN Doc. CRPD/C/GTM/CO/1 (August 31, 2016), para. 54.

older than three to be placed in residential care.²⁹ While they call for the “progressive elimination” of “large residential institutions,” they appear to endorse smaller institutions by calling them “residential care facilities.”³⁰ **In order to remedy the limitations of the UN Guidelines and to bring them into compliance with the CRPD, DRI urges the UN Committee on the Rights of the Child (CRC Committee) to issue an interpretive declaration recognizing the right of all children to live and grow up with a family consistent with both the CRC and the CRPD.**

Other UN human rights authorities have already begun to move in this direction – and to rely on CRPD protection of the right of children to live and grow up with a family. In January 2017, in its report on human rights and mental health, the UN 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.”³¹ Here 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.”³²

Obligations of Donors

Article 32 of the CRPD requires that international funding and assistance be used to advance the “purposes and objectives” of the Convention. CRPD General Comment No. 5 states that:

States parties should ensure that public or private funds are not spent on maintaining, renovating, establishing building or creating any form of institution or institutionalization. Furthermore, States parties must ensure that private institutions are not established under the guise of “community living.”³³

Given the stand the CRPD takes on the right of all children to live in a family, funding for residential institutions violates the Convention.³⁴ A recent analysis by Professor Gerard Quinn and other international experts counters the argument that smaller residential institutions could be justified as a form of “progressive achievement” toward full implementation of the Article 19:

²⁹ *Id.*, para 23.

³⁰ *Id.*, para 22.

³¹ UN Human Rights Council, Report of the United Nations High Commissioner for Human Rights on Mental Health and Human Rights, UN Doc. A/HRC/34/32, para. 58 (31 January 2017).

³² *Id.*

³³ General Comment No 5, para. 51

³⁴ Gerard Quinn, Gianne de Burca, Lisa Waddington, Mark Bell, Anna Lawson, Michael Stein, Titti Mattsson, and Luke Clements, *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). General Comment No. 5, at para. 49, allows for a very narrow exception to this rule – where funding is used specifically to protect physical safety.

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 is presumptively discriminatory. As the UN 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 non-negotiable... [T]ransitioning away from long-term care residential institutions requires foresight and planning. The planning must assume closure – and not way stations toward closure.”³⁵

This analysis is important to keep in mind as economic arguments are often put forth for the necessity of creating smaller institutions and group homes. In fact, in the long run, full integration into a family is almost certainly less costly and more cost-effective.³⁶

Conclusion

Articles 19 and 23 of the CRPD provide important new protections for children with disabilities. By prohibiting discrimination against parents with real or perceived disabilities, often wrongfully identified as “unfit,” the CRPD creates broad protections for all children. CRPD General Comment No. 5 recognizes that all children have a right to a family – and not a smaller institution or group home.

Standards for the interpretation of the right to a family, adopted to implement the CRC, have not been reviewed and updated since the entry into force and widespread ratification of the CRPD. The 30th anniversary of the Convention on the Rights of the Child and the 10th anniversary of the UN Guidelines on Alternative Care in 2019 provide an opportunity for the United Nations to review and establish unified standards for all children.

Disability Rights International calls on the international community to recognize the serious and large-scale human rights concerns of 10 million or more children detained in orphanages, institutions, and residential homes around the world. The way the problem is defined and the solutions proposed will have an enormous impact on the direction of reform. The international community must take a strong stand on the right to a family for all children – including children with disabilities.

An international review of experiences of children and their families, with and without disabilities, will strengthen the movement for reform. It would especially be valuable to have further documentation on the way discrimination against parents with real or

³⁵ Quinn *et. al.* (2018) at 15.

³⁶ General Comment No. 5 (2017), para. 5. Jim Mansell, Martin Knapp, Julie Beadle-Brown and Jeni Beecham, *Deinstitutionalization and community living – outcomes and costs: Report of a European Study Vol. 2: Main Report* (2007), available at https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf (last visited May 29, 2018).

perceived disabilities results in the improper confinement of their children. And finally, as General Comment No. 5 warns, smaller residences can be just as dangerous as larger institutions. It would be remiss to overlook the concerns of any population of children living without the protection of a family.

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