

UN Disability and Child Rights Groups On Behalf of Children without Parental Care Key Recommendations June 20, 2019

Core Principles: Right to Family Recognized Under International Law

All children have the need and the right to live and grow up with a family.¹ The preamble of the Convention on the Rights of the Child (CRC) recognizes that for their “full and harmonious development”, all children “should grow up in a family environment.” Reflecting the CRC standards, the UN Convention on the Rights of Persons with Disabilities (CRPD) sets out that the best interests of the child are the paramount consideration in all decisions affecting them (Article 7(2)), and places clear obligations on States to protect the right to family life (Article 23) and to live and be included in the community (Article 19). In the 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.”² 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.³

¹ See Eric Rosenthal, “The Right of All Children to Grow Up with a Family under International Law: Implications for Placement in Orphanages, Residential Care, and Group Homes”, 25 Buffalo Human Rights Law Review 101 (2019) (describing the development of the right to family under international law and summarizing research findings on the need and ability of all children to grow up in a family).

² 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).

³ *Id.*, para. 16(c).

CRPD General Comment No.7 recognizes the families' role by considering organizations of family members of persons with disabilities as "pivotal in facilitating, promoting and securing the interests and supporting the autonomy and active participation of their relatives with intellectual disabilities, dementia and/or children with disabilities"⁴

The undersigned disability rights, child rights and human rights organizations call on the UN General Assembly to include the following in its forthcoming resolution on the rights of children without parental care:

There are no exceptions to the right to grow up in a family for any child, and the provision of care never justifies the denial of this right. All children, regardless of disability or social background, have the same right and should be given the same opportunity to have their basic emotional needs met by living and growing up in a family and establishing the emotional bonds necessary for their healthy development.

In order to implement the right to grow up in a family, States are under the obligation to provide family support to prevent unnecessary break-up of the family. Families are the main community support and the key to facilitating community inclusion and rights protection of children with and without disabilities. Thus, it is important to preserve family relationships in order to preserve the rights of the child as well as her psychological well-being. Where children are living without parental care, governments are under the obligation to create supportive services so that children with and without disabilities have a range of options for living in the community in a family setting, including extended kinship care, foster care, or adoption, and including the maintenance of the child's sibling relationships.

Where States fail to meet their legal obligations to create the family-based support systems necessary to implement the right to family for all children, this is a human rights violation. Nevertheless, the State still has the duty to minimize the physical danger and emotional damage caused by depriving children of the right to family. States who fail in these obligations must ensure that any placement of a child in a non-family environment is only a temporary measure and that urgent steps are taken to restore the opportunity for family life. During any temporary

⁴ U.N. Secretary-General, *General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities through their representative organizations, in the implementation and monitoring of the Convention*, U.N. Doc. CRPD/C/GC/7 (Nov. 9, 2018), para. 12(d).

placement, there must be full respect for family or extended family connections that a child has, and steps must be taken to support reintegration into family life and the maintenance of connections with family, extended family, and friends in the community. The need for care, support services, treatment or education can never justify violating a child's right to family, and deprivation of family life on the basis of disability amounts to discrimination and must be prohibited by law.

For older adolescents making the transition to adulthood, the adolescent may choose to live in a community-based supported living arrangement that is not family-based. Such choice may only be viewed as informed and voluntary, however, if the adolescent is provided support to make an informed decision and after being provided the opportunity to observe, live in, and experience a safe and stable family-based setting with support services appropriate to his or her age, gender, and/or disability.

Endorsed by: Autism-Europeⁱ, Child Rights International Networkⁱⁱ, Disability Rights Internationalⁱⁱⁱ, European Disability Forum^{iv}, European Network on Independent Living^v, Inclusion Europe^{vi}, Inclusion International^{vii}, International Disability Alliance^{viii}, International Federation for Spina Bifida and Hydrocephalus^{ix}, TASH^x and Validity Foundation^{xi}

ⁱ Autism-Europe is an international association whose main objective is to advance the rights of autistic people and their families and to help them improve their quality of life. It ensures effective liaison among almost 90 member autism organisations from 38 European countries, including 26 Member States of the European Union, governments and European and international institutions.

ⁱⁱ Guided by their passion for social and legal change, the Child Rights International Network has built a global network for children's rights. They press for rights, not charity, and advocate for a genuine systemic shift in how governments and societies view children. Read CRIN code here <https://home.crin.org/the-crin-code>

ⁱⁱⁱ Disability Rights International is dedicated to promoting the human rights and full participation in society of people with disabilities worldwide. *DRI's Worldwide Campaign to End the Institutionalization of Children* seeks to draw attention to and end the pervasive and abusive practice of institutionalizing children with disabilities. DRI was established in 1993 by attorney Eric Rosenthal. Based in Washington DC, DRI documents human rights abuses publishes reports on human rights enforcement, and promotes international oversight of the rights of people with disabilities.

^{iv} The European Disability Forum (EDF) is an independent NGO that defends the interests of 80 million people with disabilities in Europe. EDF brings together representative organisations of persons with disabilities from across Europe. It was created in 1996 by its member organisations to ensure that decisions at the European level concerning persons with disabilities are taken with and by persons with disabilities.

^v The **European Network on Independent Living (ENIL)** is a **Europe-wide network** of disabled people, with members throughout **Europe**. ENIL brings together **Independent Living** organisations and individuals, and non-disabled allies, to promote the right to live independently in the community for all disabled people.

^{vi} Inclusion Europe. Ambitions. Rights. Belonging. The European movement of people with intellectual disabilities and their families. Over 70 member organisations in 39 countries.

^{vii} Inclusion International is the international network of people with intellectual disabilities and their families advocating for the human rights of people with intellectual disabilities worldwide. Together they agree on a [Statement of Unity](#) and are committed to progress towards inclusion International's vision. For over fifty years Inclusion International has been committed to the promotion of these human rights and the organization now represents over 200 member federations in 115 countries throughout five regions including the Middle East and North Africa, Europe, Africa, the Americas, and Asia Pacific.

^{viii} IDA brings together over 1,100 organizations of persons with disabilities and their families from across eight global and six regional networks. With [member organisations](#) around the world, IDA represents the estimated one billion people worldwide living with disabilities. This is the world's largest – and most frequently overlooked – marginalized group. IDA with its unique composition as a network of the foremost international disability rights organizations, is the most authoritative representation of persons with disabilities on the global level, and acknowledged as such by the United Nations system both in New York and Geneva.

^{ix} The **International Federation for Spina Bifida and Hydrocephalus (IF)** was founded by people with spina bifida and hydrocephalus (SBH) and their families in 1979. Over the years, it has grown from a voluntary association into a professional disabled people's organisation (DPO) with global coverage, democratic structure and transparent and accountable processes. The majority of IF member organisations are led and governed by adults with SBH or parents of children with SBH. Children are active participants in our members' activities: they are involved in child-led activities, training workshops on independence and holiday camps. Nowadays, many young people with SBH have taken over the leadership of their organisations. In most cases, IF members choose close cooperation with medical and education professionals and researchers, given the importance of these professions to children and adults with SBH for their survival and development.

^x TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. The TASH membership includes a diverse array of individuals and perspectives, including researchers, professionals, direct service workers, family members and people with disabilities. Together, they share a commitment to quality lives for the people for whom they advocate.

^{xi} Validity was established in 2002 as a legal advocacy organisation to tackle the generations of isolation, segregation and exclusion faced by people with mental disabilities in Central and Eastern Europe. Originally named the Mental Disability Advocacy Centre (MDAC), today Validity is a thriving network of practitioners, volunteers and partner organisations providing specialist legal support to the disability rights movements in Europe and Africa.