**Submission to the Day of General Discussion of Children’s Rights and Alternative Care**

***Protecting Children from Inherent Dangers of Institutionalization and***

***Ensuring Participation of Children with Disabilities in Decision-Making Processes***

Submitted by Disability Rights International

Disability Rights International (DRI) welcomes the Day of General Discussion’s (DGD) focus on “Children’s Rights and Alternative Care.” DRI encourages the Committee on the Rights of the Child (CRC Committee) to harmonize standards on alternative care to ensure the protection of rights also recognized under the Convention on the Rights of Persons with Disabilities (CRPD). Given the development of international law and scientific understanding, it should no longer be considered necessary or acceptable to place a child in an institution large or small – including residential care or group homes.[[1]](#footnote-1)

This submission focuses on the dangers of justifying placement of children in institutions based on the so-called “choice” of the child. Children must be protected from placement in institutions, large or small, that are inherently dangerous to their well-being, development, and protection of fundamental rights under international law. At the same time, DRI calls for the CRC to strengthen protections to ensure that all children enjoy the “right to be heard,” including children with disabilities, in all care-related decisions.

1. **All children have a need and a right to family life**

A growing body of scientific research shows that *all* children need families for their healthy emotional, cognitive and physical development.[[2]](#footnote-2) 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.” The CRPD 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 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**.” 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.

Most institutionalized children have families and are placed in alternative care due to poverty and/or disability and the stigma associated with disability, either of the child or of their parents. Children with disabilities are often left behind in child care reform programs. Evidence shows that all children with disabilities can live safely and thrive in families, no matter their support needs and they can and must be supported and accommodated to live in families.

The right to family life is only guaranteed for children when they grow up in an environment where they can form stable relations with a committed caregiver. Conversely, the right to family life cannot be guaranteed in any form of institution or non-family environment. States are under clear obligation to develop supportive services for children with disabilities and their families to facilitate the adequate exercise of parental rights and responsibilities, prevent family separation, and facilitate the inclusion of children with disabilities in the community.

***Recommendations:***

* *To guarantee that all children grow up in families, States must* ***provide adequate support for families to prevent family separation and institutionalization*** *and protect the right of parents with disabilities to keep their children. Programs should be specifically targeted to help those families most at risk – including families of children with disabilities, single mothers, and children living in poverty.*
* ***There is an immediate obligation*** *to support family-based care; available resources should be used to support families and create more family-based placements, and not for building or expanding any new large or small  institutions (whether they are called ‘residential care’, ‘group homes’, or ‘family-like units’, or similar).*
* *Governments must* ***plan for progressive elimination of institutions, including all forms of residential care and group homes****.*
* *States must* ***ensure equal access to supported family, kinship, and foster care for all children.*** *Foster care programs must be made fully accessible and appropriate for children with complex support needs, and a full range of supportive and therapeutic services must be made available to help families and prospective foster parents.*

1. **While protecting against improper institutionalization, the right to be heard should be protected for all children**

The obligation to protect children against any form of institutionalization does not and should not undermine the right to be heard. This must include a recognition of the right to be heard for children with disabilities. The obligation is on States to ensure the right to family is universal, but there may be situations – including national emergencies, war or internal conflict, and situations of mass migration – in which children are, in practice, temporarily deprived of the opportunity to be with their families. In such circumstances, it is especially important to ensure that the opinion of a child is heard in care-related decisions without discrimination.

CRC Article 12 entitles all children, including children with disabilities, to the ‘right to be heard’ in all decisions that affect them, including in the context of alternative care. It has been well-documented that children with disabilities face a higher risk of separation from their families and institutionalization than their peers without disabilities.[[3]](#footnote-3) Children with disabilities often have little or no say in decisions made by adults on with whom and where children with disabilities will live. They are excluded from decision-making processes on the basis of age or disability when the existence of cognitive or other impairments leads to a presumption of children’s incapacity for participation in decision-making processes,[[4]](#footnote-4) or when child protection workers lack skills to communicate with children with disabilities or knowledge and resources to provide disability-related supports.[[5]](#footnote-5)

The participation of children with disabilities often remains tokenistic in the absence of a range of meaningful alternatives, especially where family supports and supported foster care for children with disabilities is lacking.[[6]](#footnote-6)

Multiple studies have shown that children in alternative care face barriers to participation in child care proceedings, while in care and while plans for leaving care are being devised.[[7]](#footnote-7) Barriers to participation may include: perception of children in care as particularly vulnerable and lacking agency, adult-centric models of decision-making that exclude children’s views,[[8]](#footnote-8) a lack of training and skills of child protection workers to communicate with children, risk aversion of child protection workers resulting in lack of opportunities for children, lack of child-friendly review and complaint mechanisms in systems of care, or lack of supportive persons of trust for a child. Research has also shown that younger children, children with experience of multiple previous care placements, and children with disabilities are given fewer opportunities to participate, express their views, and influence decision-making processes.[[9]](#footnote-9)

Protection and participation are complementary rather than in opposition, and research has shown that children’s participation in the context of child protection services increases their confidence, self-efficacy and self-worth.[[10]](#footnote-10) The evidence shows that children want to be involved in decisions related to their care, such as where and with whom they will live or how often they see their family members while in care.[[11]](#footnote-11) However, it is very common that at best children are only allowed to have their say in trivial decisions, while in decisions which matter to them the most, such as where they live or how often they will see their birth parents, they have little to no say,[[12]](#footnote-12) or are even denied a chance to express their views by giving evidence in courts in care proceedings to prevent them from being exposed to distress.[[13]](#footnote-13)

**The right to be heard should never be used to undermine protection against institutionalization.** Proponents of small-scale residential care argue that children’s preferences may justify placement in residential care facilities.[[14]](#footnote-14) Children’s apparent ‘preference’ for small-scale residential care may be due to ‘adaptive preferences’[[15]](#footnote-15) based on the lack of experience with any safe and meaningful alternative. Adverse experiences in poorly organized and administered foster care programs may also be used to justify investments in residential care for some children, in particular children with disabilities. A decision between inadequate foster care and any form of institution is not a real or meaningful choice.

Despite this, expressions of preference in this context may be positive for the child. **Such expressed preferences** ***should be understood as a signal to develop better forms of family-based care responsive to children’s needs rather than a justification for placing children in harmful living conditions in residential care.***

The obligation to protect the best interest of the child under the CRC requires States Parties to protect children from institutional placement. Some proponents of small group homes have argued that it is sometimes children’s “choice” to live in residential care rather than a family. Such choices cannot be justified by international law which does *not* endow children with the full legal capacity or adult-like autonomy to place themselves in situations of inherent danger***.***

CRC Article 12 is both a substantive right and a general principle to be applied across all other rights enshrined in the CRC. It does not entitle children to the right to make choices, but to participate in decisions in all matters that affect their lives.

The ‘right to be heard’ means that children have the right to: a) be informed about what is at stake when decisions such as placement in care are being made b) express their views; c) have that view considered seriously by adult decision-makers; and d) get feedback if a course of action different than their view had to be taken.

Children must be offered viable alternative care options which aim to restore their right to family life. Authorities have a duty to take concrete steps to establish a range of family-based alternatives for children with disabilities who get separated from their biological families. Such alternatives must be presented to children with disabilities facing placement in alternative care or preparing to leave institutional care, in an accessible manner. Children should only be given options of family-based alternatives which do not constitute harm for their development (e.g. foster care, kinship care). In countries where authorities have failed to establish systems of family-based care, the participation of the child amounts to tokenism as the child does not have family-based alternatives to choose from.

***Recommendations:***

* ***No child should ever be presented with a choice to live in any form of institutional care.*** *If temporary placement in some form of institutional care remains the only option offered by an inadequate child care system, the child must be informed of steps to be taken to restore their right to family life. Such a decision cannot ever be justified as being in the child’s best interests or resulting from the child’s choice. A clear plan must be devised to move the child to a family-based setting as soon as possible.*
* *The Committee should acknowledge that children’s wishes must be balanced against their ‘best interests’ and that* ***children should never be allowed to choose options which are likely to result in significant harm,*** *such as the harm caused by living in any form of institutional care settings. The participation of children in decisions on placement in alternative care is only meaningful when a range of family-based alternatives are available to guarantee the right to family life.*
* *The Committee should call on States Parties to* ***design inclusive and child-friendly mechanisms for child participation in all care-related judicial and administrative proceedings*** *with the provision of disability-related supports where needed.*

1. **The CRPD Committee expressed in its General Comment No. 1 that mental capacity assessments lead to denial of rights to persons with disabilities.[[16]](#footnote-16) Mental capacity assessments are often used to deny parental rights to persons with disabilities and restrict the right of children with disabilities to be heard.**

CRPD Article 7 (3) does not impose any conditions on children with disabilities to express their views, unlike CRC Article 12, which confers this right only to the children who are capable of forming a view. Interpreted in conjunction with the stance of the CRPD Committee, it follows that differences in mental capacities or cognitive abilities should never be the reason to deny children the right to be heard, including in the context of alternative care. Instead of focusing on normative stages of development and assessments of children’s capacities and competence to take part in decision-making processes in the context of alternative care, the focus should shift onto the competence of adults involved in children’s care to enable them to participate and maximise children’s capacities through the provision of age-appropriate and disability-related supports.[[17]](#footnote-17)

***Recommendations:***

* ***The existence of any type or level of impairment should never justify denial of parental rights to parents with disabilities or the right of a child to express their views in the context of alternative care.*** *Age-appropriate and disability-related supports, including peer support by young people or adults with disabilities who might share similar care experiences, should be provided where needed for a child to express views and their wishes to be ascertained.*

1. **Participation of children with disabilities as a collective and their representative organizations in the context of alternative care**

The right to be heard encompasses the right of all children to participate collectively in strategic decision-making processes, such as policy-making or preparation of laws[[18]](#footnote-18) or monitoring and evaluation of care services. When planning the development or transformation of alternative care systems and services, the best interests of a large group of children are at stake and States Parties should provide opportunities to hear from children whose interests are at stake and include them in the process of planning legislative decisions or other actions.[[19]](#footnote-19)

Children with disabilities face an increased risk of being left out of these processes as a group due to presumptions of incapacity and a lack of supports for their meaningful participation. The CRPD Committee has emphasized in General Comment No. 7 that organizations of children and young persons with disabilities are fundamental for the realization of the right to be heard and their participation in public life.[[20]](#footnote-20)

***Recommendations:***

* ***States Parties should design mechanisms to support children in care, including children with disabilities, to participate collectively in strategic decision-making processes regarding legislative and policy-making processes in the area of alternative care.****[[21]](#footnote-21) States Parties should also ensure that children in care are provided with supports for self-advocacy and supports to establish formal and informal groups to represent their interests in the context of alternative care.*
* ***DRI encourages the CRC Committee to adopt guidiance to emphasize the significance of the participation of civil society.*** *In addition to encouraging child participation, it is essential to include organizations of persons with disabilities made up of adults and young people with disabilities in strategic decision-making processes. Institutions will never be fully eliminated until society is made inclusive for children and adults with disabilities, and collaboration with disability rights groups is essential to bring about this transformation of care.*

1. 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’ (2018) 25 Buffalo Human Rights Law Review 65. [↑](#footnote-ref-1)
2. Marinus H van IJzendoorn and others, ‘Institutionalisation and Deinstitutionalisation of Children 1: A Systematic and Integrative Review of Evidence Regarding Effects on Development’ (2020) 7 The Lancet Psychiatry 703; Anna T Smyke and others, ‘The Caregiving Context in Institution-Reared and Family-Reared Infants and Toddlers in Romania’ (2007) 48 Journal of Child Psychology and Psychiatry, and Allied Disciplines 210. [↑](#footnote-ref-2)
3. Chris Desmond and others, ‘Prevalence and Number of Children Living in Institutional Care: Global, Regional, and Country Estimates’ (2020) 4 The Lancet Child & Adolescent Health 370; 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’ (2018) 25 Buffalo Human Rights Law Review 65. [↑](#footnote-ref-3)
4. Davis and Watson, ‘Disabled Children’s Rights in Every Day Life: Problematising Notions of Competency and Promoting Self-Empowerment’ (2000) 8 The International Journal of Children’s Rights 211. [↑](#footnote-ref-4)
5. Anita Franklin and Patricia Sloper, ‘Supporting the Participation of Disabled Children and Young People in Decision-Making’ [2009] Children & Society 3. [↑](#footnote-ref-5)
6. *See, for example,* Disability Rights International. "A Dead End for Children: Bulgaria's Group Homes." Available at SSRN 3664732 (2019). [↑](#footnote-ref-6)
7. Michael Gallagher and others, ‘Children and Families’ Involvement in Social Work Decision Making’ (2012) 26 Children & society 74; Caroline Leeson, ‘My Life in Care: Experiences of Non-Participation in Decision-Making Processes’ (2007) 12 Child & Family Social Work 268; Mijntje DC Ten Brummelaar and others, ‘Participation of Youth in Decision-Making Procedures during Residential Care: A Narrative Review’ (2018) 23 Child & family social work 33; Jill Duerr Berrick and others, ‘Children’s Involvement in Care Order Decision-Making: A Cross-Country Analysis’ (2015) 49 Child abuse & neglect 128. [↑](#footnote-ref-7)
8. Manuela Garcia-Quiroga and Irene Salvo Agoglia, ‘Too Vulnerable to Participate? Challenges for Meaningful Participation in Research With Children in Alternative Care and Adoption’ (2020) 19 International journal of qualitative methods 160940692095896. [↑](#footnote-ref-8)
9. Gallagher and others (n 9); Ten Brummelaar and others (n 9). [↑](#footnote-ref-9)
10. Jeanette Cossar, Marian Brandon and Peter Jordan, ‘“You’ve Got to Trust Her and She’s Got to Trust You”: Children’s Views on Participation in the Child Protection System’ (2016) 21 Child & family social work 103 [↑](#footnote-ref-10)
11. Judy Cashmore, ‘Promoting the Participation of Children and Young People in Care’ (2002) 26 Child abuse & neglect 837; Aoife Daly, *Children, Autonomy and the Courts: Beyond the Right to Be Heard* (BRILL 2018 [↑](#footnote-ref-11)
12. Munro, ‘Empowering Looked-after Children’ (2001) 6 Child & family social work 129; Ten Brummelaar and others (n 9) [↑](#footnote-ref-12)
13. ly (n 13). [↑](#footnote-ref-13)
14. Grigoras (n 5). [↑](#footnote-ref-14)
15. Tania Burchardt \*, ‘Capabilities and Disability: The Capabilities Framework and the Social Model of Disability’ (2004) 19 Disability & Society 735. [↑](#footnote-ref-15)
16. Committee on the Rights of Persons with Disabilities, ‘General Comment No. 1 (2014) Article 12: Equal Recognition before the Law’ (2014) CRPD/C/GC/1 1. [↑](#footnote-ref-16)
17. Tisdall (n 26); Annemie Dillen, ‘Children between Liberation and Care: Ethical Perspectives on the Rights of Children and Parent-Child Relationships’ (2006) 11 International Journal of Children’s Spirituality: Children’s Spirituality and Children’s Rights 237; Carine Le Borgne and E Kay M Tisdall, ‘Children’s Participation: Questioning Competence and Competencies?(Report)’ (2017) 5 Social Inclusion 122. [↑](#footnote-ref-17)
18. Committee on the Rights of the Child (n 29). para.12 [↑](#footnote-ref-18)
19. ibid. para.73 [↑](#footnote-ref-19)
20. CRPD Committee, ‘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\*’ 7. para. 12 (f) [↑](#footnote-ref-20)
21. Examples of children and young people’s participation through advisory bodies set up within the national independent human rights institutions may serve as a good practice, such as the Panel of Youth set up as advisory bodies of the Ombudsman and the Commissioner for Equality Protection in the Republic of Serbia. [↑](#footnote-ref-21)