

INCLUSION INTERNATIONAL SUBMISSION
to the 2021 Day of General Discussion of the CRC on
Children's Rights and Alternative Care

Introduction

1. Inclusion International welcomes the initiative by the Committee on the Rights of the Child to hold a Day of General Discussion on Children's rights and alternative care, and appreciates the opportunity to provide a written submission to contribute to the debate.
2. Inclusion International (II) is the global network of people with intellectual disabilities and their families. For over 60 years, II has been committed to the promotion of the human rights of people with intellectual disabilities, focusing on key issues including access to inclusive education, deinstitutionalization, legal capacity, inclusion in the community, self-advocacy and support to families. At the global level, and at the national and local level through its membership, II advocates for the inclusion of persons with disabilities into their communities, which includes raising children within their families.
3. This submission is the product of consultation with II members from 16 countries from Asia, Europe, MENA, Latin America, Africa and North America.¹

Basic principles

4. Children with intellectual disabilities should be recognised as having the same rights as all other children and they should receive the supports they require to realize that right.
5. Inclusion International believes that ALL children should grow up in a family. Disability should never be a reason for depriving a child of their right to family life, or for being separated from their families.
6. All children with disabilities, including children with high support needs, have the right to a family life, the right to receive an inclusive education, and the right to grow up in their community.
7. II defines an institution as "Any placement of children in a residential setting outside a family". The use of "institution" in this document refers to all kinds of alternative care that are not kinship care or foster care. Small group homes are considered as institutions.

Facts about institutional alternative care

8. Nine of seventeen surveyed members of II shared that for children with intellectual disabilities, placement in institutions is the most commonly used form of alternative care. Kinship care is the second most common type of alternative care recognized and used for children with intellectual disabilities, followed by foster care.

¹ Taiwan, Myanmar, Bangladesh, Nepal, UAE, Lebanon, Israel, Germany, Norway, Denmark, Ecuador, Colombia, Argentina, USA, Benin, Uganda

9. In countries where institutions are the most common form of alternative care, it was reported from the members that quality of care in institutions is very poor. Members report a lack of supervision by authorities in particular for private institutions. The high number of sexual crimes and other forms of violence and abuse have also been raised by II members as a key risk for people in institutions.
10. Institutions provide different kinds of services, with a focus on medical and paramedical services. Children with disabilities are considered patients rather than children who need support to evolve their development and skills which correspond to the medical model of disability instead of a social model that focus on participation. According to one of the survey's respondents, children in institutions receive only basic learning "to be clean, to eat alone, not to disturb, and to be polite". Receiving all the services at one place prevent them from interacting with peers in inclusive environments and do not allow them to grow up like other children within their communities.
11. Some respondents to the survey shared that professionals within institutions do not have the knowledge and the skills to work with children with intellectual disabilities.
12. Children living in institutional settings and deprived of a family environment face mental health issues. Four of the surveyed members mentioned mental health as a main challenge faced by children with intellectual disabilities in institutional settings.
13. One II member shared that children with disabilities have a path of care that is different from other children. They are taken to institutions only for children with disabilities, where it is very difficult to access adoption processes.
14. One of the surveyed members shared that over 45% of children in alternative care in their country are children with disabilities.

Reasons for separation

15. Half of the surveyed members answered that lack of support for families is the main reason for the separation of children from their families, followed by the absence of parents as second reason (because of death, prison, or other).
16. Children with high support needs are overrepresented in institutions. Parents of these children are encouraged to place their children in institutions for a better quality of care and for their "best interest".
17. When parents have a disability themselves, this also can lead to separation. Because of the lack of support, parents with disabilities are encouraged to abandon their children.
18. In many countries, families are encouraged to abandon their children with disabilities. This pressure comes from the government, the society and professionals.

Good practices from the field

19. In Israel, a foster care law was enacted in 2016. The foster law regulates the placement of children in foster families when the overriding consideration is the child's best interests. The Ministry of Welfare is authorized to provide a license for foster families that indicates eligibility and suitability. The law anchors, among other things, the need for guidance and support to the foster families and create a monitoring mechanism.

20. In Norway, when a child has an intellectual disability and the parents experience a heavy burden of care, local authorities are obligated to provide the family with necessary support. The local authorities have to take into account what the family wants. In-home support is often organized as user-led personal assistance, where the parents decide who gives the support, when the support is given, and what the help shall consist of.
21. “United families” is a program that targets families where parents are persons with disabilities. This program provides intensive support and assistance for both parents and the children in order to prevent abandonment.
22. In Kenya, a network of parents has been created by parents of children with disabilities. It is a peer support group of parents that offer respite care for parents who need relief. The network of families receives the child at home within their families for a short period of time in order to allow the parents to go to work, to have some relief, etc.

Impact of COVID19 on children with disabilities in alternative care

23. Many members shared that in their countries, no data was collected nor shared on how children with intellectual disabilities living in the institutions were impacted during the pandemic.
24. The mental health of children with intellectual disabilities was strongly impacted during the pandemic, in particular during the lockdown period.
25. Children with intellectual disabilities in institutions were sent back home and no support was offered to families.
26. Children with disabilities who lives in institutions in a permanent basis were denied visits from their families in the institution, and were even prevented from going for short visits to their families.

Recommendations

27. Improve laws and policies on child care including for children with disabilities, and make them compliant with the CRC and CRPD.
28. Raise awareness within communities about child care in order to encourage foster care, in particular for children with disabilities and the most marginalized groups of children.
29. Budgets and funding commitments to build and “improve” the quality of institutions should be transferred to the community and instead fund assistance and support to families so they can keep their children with disabilities at home.
30. Improve data collection on children in alternative care and use disaggregated data. Data collection should include regular supervision and quality assessments of institutions and the services provided.
31. Civil society organizations including OPDs should be allowed to visit and monitor institutions so they can ensure rights are not being violated, provide assistance, report to the government, and provide adequate recommendations.
32. In many countries, kinship care is the main and natural form of alternative care for children. Governments should support and encourage kinship care and foster care by providing the necessary support in the community and in-home.

33. Facilitate adoption programs and procedures and encourage adoptive parents to welcome children with disabilities into their family.
34. In order to prevent separation and abandonment, governments should provide all of the necessary support (technical, financial, emotional, etc.) to families of children with disabilities, including encouraging the development of peer support groups and networks.
35. Develop inclusive community services and support services for children with disabilities and their families and ensure that information on the existing services are available and accessible to them.
36. Support services to families should be user-led and personalized in order to correspond to each child and family's needs.
37. Persons with disabilities who want to become parents should be supported in order to prepare them and accompany them. Support should be adapted to their needs
38. Early childhood programs should be trained in order to help parents of children with disabilities and provide them with guidance and information instead of encouraging them to use alternative care.
39. Social protection measures should consider the role of the carer of the child with disability as well as the disability-related extra costs. There is an important economic impact of caring a child by a parent which make them in a position of choosing between caring their child and losing the job or placing the child with disability in an institution in order to maintain the financial income of the home.