

Safeguarding the rights of children with disabilities in alternative care

This briefing noteⁱ is designed to:

- highlight the special vulnerability of children with disabilities who are in alternative care,
- encourage members of CRPD Committee to consider the potential added value of reference to the Guidelines for the Alternative Care of Children (Guidelines) in developing their arguments and recommendations, especially when reviewing State Party reports

Children with disabilities in alternative care:

Millions of children around the world cannot live with their parents, for a wide variety of reasons. While the majority are cared for on an informal basis by relatives or others in their immediate community, a significant proportion are placed in “formal” settings: with foster parents or residential care – in the case of most countries – more frequently in large institutional facilities.

All children without or at risk of losing parental care are particularly vulnerable – hence, indeed, the development and acceptance of the Guidelines by the UNGA. However within this group, children with disabilities are clearly among those most at risk:

- Enhanced recourse to alternative care for these children stems from parents’ felt-inability to cope – and lack of available support of all kinds to do so – and, in many societies, the prevailing stigma associated with having a child with disability. The disability of a child can therefore be a factor leading to their abandonment or relinquishment. This was confirmed in a regional analysis in 2011 of causes of separation in Latin America.ⁱⁱ International Disability Alliance has also noted that “the widespread stigma attached to persons with disabilities, combined with the strict family planning policy in China renders children with disabilities at a high risk of being abandoned by parents and placed into institutions”.ⁱⁱⁱ
- When children with disabilities are abandoned and/or separation from their families becomes necessary, there is an unequal provision of family and community based options for them. For example, options such as foster care and adoption are less available, often due to lack of resources being invested into training and preparation of potential families.^{iv} This is often exacerbated by the fact that the specific needs of children with disabilities in alternative care are not covered by national legislation, as is the case in Argentina.
- Scarce options often result in a significant over-representation of children with disabilities in institutions. Whilst limited statistics are available, a 2012 report documents “that in CEE/CIS states ... more than one third of children in residential care have disabilities, with most of these children placed in large-scale institutions ... The rate of institutionalization of children with disabilities has stayed the same over the past 15 years, even when the rate has fallen for other groups, suggesting that children with disabilities have largely been ignored in reform efforts (UNICEF 2010)...”.^v In Hungary, there were 1,862 children with disabilities in

residential care in 2010, representing 27% of the total number.^{vi} In China, “evidence also clearly suggests a high rate of institutionalization for children with disabilities”.^{vii}

- Research consistently shows that children are exposed to risks of abuse and violence in institutional settings.^{viii} Furthermore, “institutional care is expensive, much more so than support to parents or family-based care. In the long run, if poor care exacerbates disability or provides inadequate opportunities for helping those with disabilities to learn to live independently, children with disabilities will continue to need the support of the state long into adulthood.”^{ix} For example, in countries such as Cote d’Ivoire and Viet Nam, children with disabilities, continue to live in State-run institutions well into adulthood.

International Conventions including the UN CRPD provide general protection for children with disabilities in alternative care:

The UN Convention on the Rights of the Child (UN CRC) as well as other key international conventions including the UN CRPD have provisions to address the above situation. They recognise the child's right to be cared for by his or her parents wherever possible, and set out States Parties' obligations to provide suitable alternative care if this becomes necessary.

The UN CRPD affords children with special protections as explicit in article 14 (equal rights for children), article 19 (equal right to independent living) and article 23 (right to enjoy family life). Article 23 states that children with disabilities have equal rights to live within a family environment and should be afforded the means to do so. Article 23 specifically stipulates that *“to prevent concealment, abandonment and neglect of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families ... 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”*. Article 23 further states that *“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.”*

UN Guidelines on Alternative Care – supplementary protection for children with disabilities:

Grounded in the CRC in particular, the UN Guidelines for the Alternative Care of Children not only set out more detailed policy orientations regarding appropriate care provision for all children but, in addition, contain at least ten specific references to children with special needs in alternative care settings. Among these are:

- Para 9: “[...] States should seek to ensure appropriate and culturally sensitive measures... [t]o support family caregiving environments whose capacities are limited by factors such as disability...”
- Para 10: “Special efforts should be made to tackle discrimination on the basis of any status of the child or parents, including ... mental and physical disability.”
- Para 34 (b): “Supportive social services ... and services for parents and children with disabilities. Such services, preferably of an integrated and non-intrusive nature, should be directly accessible at the community level and should actively involve the participation of families as partners, combining their resources with those of the community and the carer.”

- Para 38: “States should ensure opportunities for day care, including all-day schooling, and respite care which would enable parents better to cope with their overall responsibilities towards the family, including additional responsibilities inherent in caring for children with special needs.”
- Para 58: “[Assessment] should take into account the child’s immediate safety and well-being, as well as his/her longer term care and development, and should cover the child’s personal and developmental characteristics, [...] medical history and any special need.”
- Para 86: “Carers should ensure that the right of every child, including children with disabilities, living with or affected by HIV/AIDS or having any other special needs, to develop through play and leisure activities is respected and that opportunities for such activities are created within and outside the care setting. Contact with the children and others in the local community should be encouraged and facilitated.”
- Para 87: “The specific safety, health, nutritional, developmental and other needs of babies and young children, including those with special needs, should be catered for in all care settings[...].”
- Para 117: “Agencies and facilities [responsible for formal care] should ensure that, wherever appropriate, carers are prepared to respond to children with special needs, notably those living with HIV/AIDS or other chronic physical or mental illnesses, and children with physical or mental disabilities.”
- Para 132: “Children with special needs, such as disabilities, should benefit from an appropriate support system [in relation to process of transition from care], ensuring, inter alia, avoidance of unnecessary institutionalization.”

Children with disabilities need to benefit from such protections in order to:

1. Ensure that children with disabilities do not find themselves in alternative care unnecessarily; and
2. That where out-of-home care is provided, it is delivered under appropriate conditions responding to the child's rights and best interests

Recommendation:

Given the significant policy orientations relevant to children with disabilities – who are subject to higher risk of separation as well as often over-represented in alternative care settings – by the Guidelines, it is respectfully suggested that the CRPD have regard to the Guidelines when examining State Parties’ reports and reflect them in their Concluding Observations, as is being regularly done by the CRC.^x Since the CRC does not always explicitly address the issue of children with disabilities in alternative care, such an initiative on the part of the CRPD would constitute a vital step towards ensuring that children with disabilities are less discriminated in alternative care matters.

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Further reading:

- Better Care Network <http://www.crin.org/BCN/initiatives.asp>
- Better Care Network and EveryChild, Enabling Reform: Why supporting children with disabilities must be at the heart of successful child care reform http://www.crin.org/docs/Enabling%20Reform_March2012.pdf
- International Social Service <http://www.iss-ssi.org/2009/index.php?id=25>
- NGO Group for the CRC (UN translations) <http://www.childrightsnet.org/NGOGroup/childrightsissues/WithoutParentalCare/>
- RELAF (child and adult friendly version) <http://www.relaf.org/aplicacion.html> and http://www.relaf.org/aplicacion_eng.html
- SOS- Children's Villages International <http://www.sos-childrensvillages.org/What-we-do/Child-Care/Quality-in-Care/Advocating-Quality-Care/Pages/UNGuidelinesontheAlternativeCareofChildren.aspx>
- UNICEF http://www.unicef.org/protection/57929_58004.html

Annex 1: Development of the Guidelines

The need for detailed international standards to address the situation of children deprived of their family or at risk of being so was first pinpointed by UNICEF which, in 2004, allied itself with International Social Service to produce evidence-based documents in support of developing such an instrument. These joint efforts bore fruit in 2005, when the United Nations Committee on the Rights of the Child held a day of general discussion on children without parental care. In its final report, the Committee recommended that the international community prepare a set of international standards for the protection of children without parental care for the UNGA.

A draft text was submitted for consultation at an intergovernmental meeting convened by Brazil in August 2006. Subsequent consultations were held in Cairo, Geneva and New York with interested Governments, UN Agencies, NGOs and young people with experience of alternative care. In 2009, a text was agreed upon and on June 17, 2009 the Human Rights Council adopted by consensus a procedural resolution A/HRC/11/L.11 submitting the "Guidelines for the Alternative Care of Children" for the consideration of the UNGA.

The Guidelines were formally endorsed at the 3rd Committee on 20 November 2009 and later welcomed by consensus in the UN General Assembly (UNGA).

ⁱ Prepared by Mia Dambach, including feedback from Nigel Cantwell and Alan Kikuchi-White, submitted 17 September 2012

ⁱⁱ Informe Latinoamericano Situación de la niñez sin cuidado parental o en riesgo de perderlo en América Latina Contextos, Causas y Respuestas at p 39 <http://www.relaf.org/Informe%20Latinoamericano.pdf>

ⁱⁱⁱ International Disability Alliance submission to the CRPD at p 17 <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session7.aspx>

^{iv} Better Care Network and EveryChild, Enabling Reform: Why supporting children with disabilities must be at the heart of successful child care reform at p 13 available at http://www.crin.org/docs/Enabling%20Reform_March2012.pdf

^v Op cit at p 12

^{vi} Transmonee statistics

http://www.transmonee.org/Gallery_en/7_Children_with_and_without_disabilities_in_residential_care.htm

^{vii} Better Care Network and EveryChild, Enabling Reform: Why supporting children with disabilities must be at the heart of successful child care reform at p 12 http://www.crin.org/docs/Enabling%20Reform_March2012.pdf

^{viii} <http://www.violencestudy.org/r242>

^{ix} Better Care Network and EveryChild, Enabling Reform: Why supporting children with disabilities must be at the heart of successful child care reform at p 12 available at http://www.crin.org/docs/Enabling%20Reform_March2012.pdf

^x An analysis of the CRC's recommendations over the last two years shows that the Committee regularly makes recommendations to apply the UN Guidelines on Alternative Care of Children (e.g.: Turkey, Viet Nam, Cook Islands, Madagascar, Myanmar, Thailand, Italy, Panama, Korea, Seychelles, Syria, Bahrain, Cambodia, Costa Rica, Czech Republic, Egypt, Finland, Afghanistan, Belarus, Denmark, Laos, Singapore and Ukraine).