

# Better Care Network Netherlands



## ‘Family-based care for children with disabilities in low- and middle-income countries’

Overview of materials, tools and publications  
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## 'Family-centered versus residential care'

Children with disabilities can be taken care of in many different ways: from care within their family, care by the extended family, care in foster families, care in small-scale family homes to different types of residential care. The international Convention on the Rights of the Child states that 'the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding'. This does not mean that a child has an absolute right to a family, however it does imply that alternative forms of care, based on a family environment, are preferred in case a placement in alternative care is in the best interest of the child.

One of the reasons a family environment is preferred is because growing up in residential care has numerous negative effects on children, with children with disabilities at an even greater risk.

Yet many children in the Global South reside in institutional care, because of:

- Practical reasons, such as inaccessible roads, no special or accessible school nearby, no therapy.
- Family-related reasons, such as poverty and family members not being able to take care of the child.
- Cultural/social reasons, such as the effect of stigma on the child and the family.
- Procedural reasons, such as legislation stating that a child cannot be placed in a (temporary) alternative family environment and must be taken to a children's home.

With this overview, we hope to inspire organisations and give them tools to provide family-based care. Not only for children with disabilities, but also for families where a parent is disabled. Families in this situation often struggle and run a greater risk of falling apart, for example due to poverty or because the partner without a disability finds a new partner.





## International legislation and regulations

What international frameworks apply to the care of children with disabilities?

- [UN Convention on the Rights of the Child](#) (1989): 'Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community' (preamble). This convention is ratified by all countries, except for the US.
- [Convention on the Rights of Persons with Disabilities | OHCHR \(2006\)](#): 164 countries are party to this treaty. It states, for example: 'State Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities (...) (article 23.3) and 'State Parties shall, 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' (article 23.5).
- [The Missing Billion Report](#) and follow-up reports. [Reimagining Health Systems \(2022\)](#): the first report dates back to 2019 and was written and signed to address inequality and challenges in access to care for people with disabilities. The follow-up report aims to provide new insights in health outcomes and discuss the gaps in health systems for people with disabilities, to present a vision for an inclusive health care system and to translate this vision to a practical Missing Billion Road Map to 2030.
- [Joint Statement: The Rights of Children with Disabilities | Better Care Network \(2022\)](#). Joint statement of the UN Committee on the Rights of the Child & the UN Committee on the Rights of Children with Disabilities: 'Both Committees are deeply concerned about the institutionalisation of children with disabilities and call on States Parties to end institutionalisation on the basis of disability and to promote the development of support for children in a family in the community.'
- [Guidelines on Deinstitutionalization, including times of emergency \(2022\)](#): these guidelines provide a road map for governments, activists and donors on the necessary steps to take to stop institutionalisation and residential care for people with disabilities: 'Institutionalisation is a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention. (...) State parties should recognize institutionalization as a form of violence against persons with disabilities.'
- Where can I find whether the government of my project country signed the UN Resolutions? Check this website: [CRPD List of Countries by Signature : Confirmation : Accession : Ratification | Disabled World \(disabled-world.com\)](#)
- There are also various other laws and regulations at regional level, such as the [African Charter on the Rights and Wellbeing of the Child](#)



### Materials for children

- [It's about Ability | UNICEF](#) This publication explains the Convention on the Rights of Persons with Disabilities to children.

### Background information about children with disabilities

- [Factsheet van UNICEF \(2022\)](#) about the situation of children with disabilities worldwide.
- ['Seen, Counted, Included' \(2023\)](#): a comprehensive overview by UNICEF with more than sixty indicators of child well-being – from nutrition and health, to access to water, protection from violence and exploitation, and education. This report, which is based on all recent data currently available, also includes

the first-ever global and regional estimates of children with disabilities. It is available in English, Arabic, French and Spanish.

- [Overzicht van onderzoeken van UNICEF](#) about the situation of children with disabilities.
- Free course on global health and disabilities via [Global Health and Disability - Online Course \(futurelearn.com\)](#). In this free three-week course, which you can do at your own pace (study load approx. four hours per week), you will learn about the extent, definitions and challenges of people with disabilities and how health care and rehabilitation can be improved. It provides proper insight into different views on disabilities and the necessary and achievable steps to improve the situation of adults and children with disabilities.
- David Werner's publications [Disabled Village Children: A guide for community health workers, rehabilitation workers and families \(1987\)](#) and [Nothing About Us, Without Us: Developing innovative technologies for, by and with disabled persons \(1998\)](#) are classics and still worth reading.
- How do I know what the specific problems are in my project country? Check the reports of the Committee on the Rights of Persons with Disabilities (CRPD) and the shadow reports made by NGOs through <https://www.ohchr.org/en/treaty-bodies/crpd>. Also check with INGOs that work in these countries and possibly work with your partner.



### **Factors that contribute to families falling apart**

What makes children lose their families to end up in alternative care, and which factors contribute to the fact that alternative care is an 'attractive' option for parents?

- Families with a disabled child have a greater chance of poverty and extreme poverty (due to the additional care costs).
- Sometimes there is a stigma attached to having a child with disabilities, which sometimes even leads to the abandonment of the child, or the repudiation of the mother and child from the family.
- A lack of special and inclusive education nearby families.
- A lack of good day care for the child, as a result of which parents cannot work or work less.
- A lack of (physical or financial) access to medical, paramedical and/or educational support and/or support to increase family income.
- A lack of support and services within the local community, including help with behavioural problems children may have.
- A lack of accessible transport.
- A lack of accessible housing and/or aids to promote mobility and independence.
- In some countries, legislation states that children cannot be placed in a (temporary) alternative family environment and must be taken to a home.
- It is often thought that institutions are better capable of providing specialised care, good education and good nutrition to the child, while this is not available in the home situation.







### Prevention/empowering the family

What good materials and resources are available to work on preventing children from losing their families and to empower families?

- [UNICEF Parenting](#) | UNICEF Parenting contains many resources to support parents in giving their children a good start in life.
- [Disability Toolkit | Changemakers for Children](#) contains many resources and tools to help parents, family members and care takers to better understand their child with a disability and to match with their rights and needs.
- [Parent and family leadership in preventing institutionalization of children with disabilities: Promising practices from countries in transition- COSP13 Side Event | Better Care Network \(2020\)](#). In this video, experts from Moldova, South Africa, Burkina Faso, Vietnam and the US talk about their experience to empower parents in their role and how children with disabilities can grow up within their family.
- [Family Care for Children with Disabilities: Practical guidance for frontline workers in low- and middle-income countries \(2018\)](#) is a practical guideline for people working with children and their families in low- and middle-income countries and provides information on how to work with children with disabilities and their families.
- [Disability Inclusion in Family-Based Care: Part One | Better Care Network \(video, 2019\)](#) on the experiences of family-based care for children with disabilities in Cambodia.
- [Webinar Recording: Nurturing Care For Children With Developmental Delays And Disabilities | Better Care Network \(2020, video\)](#) explores the challenges and research in Kenya, Mozambique, Tajikistan and Peru on supporting children with developmental delays and disabilities.
- [Niketan Modules](#) Childhood development and disability.
- Enablement publications and materials (mostly free to download) via [Publications Archive - Enablement](#):
  - [RehApp](#): free app with basic information and advice on different types of disabilities.
  - [RehApp Flashcards - Enablement](#) : the hardcopy version of the chapters in RehApp: please contact [l.guignard@enablement.nl](mailto:l.guignard@enablement.nl) if you would like to translate these in other local languages.
  - [Pocket cards Tools - Enablement](#). an older, shorter version of the basic information about 14 common disabilities.
  - [Tip sheets](#) for community workers and parents: about eating and drinking, communication, active lifestyle, epilepsy (under development: play, food and nutrition for children with severe multiple disabilities)
  - [Workshop manual](#) for making toys with parents.
  - Development Chart: poster of developmental milestones between 0 and 8 years old. Available on request from the Liliane Fonds ([akester@lilianefonds.nl](mailto:akester@lilianefonds.nl)) in: English, French, Spanish (soon), Vietnamese, Swahili and Luganda.
  - [Roads to Inclusion: Tools - Enablement](#). Developed by Enablement and Light for the World to provide Community Based Rehabilitation (CBR) teams with local support in examining whether their village/area/project is disability-inclusive.

### Early Childhood Intervention

- [What is Early Childhood Development? A Guide to Brain Development \(harvard.edu\)](#).
- European Association on Early Childhood Intervention [EURLYAID - E.A.E.C.I.](#)
- European Association of Service providers for Persons with Disabilities [EASPD Family Centered Early Childhood Intervention](#).
- [Integrale Vroeghulp](#) video in Dutch.
- [African Early Childhood Network webinars](#).
- Special from the Liliane Fonds on early recognition, acknowledgement and intervention, based on the WHO's Nurturing Care Framework. [Vol verwachting: online special | Liliane Fonds](#) (in Dutch).
- WHO tools on 'Nurturing Care': [Nurturing Care Framework for Early Childhood Development \(WHO\)](#). Child Health and Development (who.int).
- WHO tools aimed at children with developmental disabilities including autism: [Caregiver Skills Training WHO](#). [WHO eLearning Caregiver Skills Training for Families of Children with \(openwho.org\)](#) + [Mental Health and Substance Use \(who.int\)](#).
- Niketan has [various videos](#) to train parents/caretakers/supervisors on the physical development of children with disabilities in particular.

### Pleegzorg

- [Using the Deaf Community as an Alternative Treatment Strategy: Developing Deaf Treatment Foster Homes | Better Care Network](#): article on foster care for hearing-impaired and deaf children.
- [Disability Inclusion in Family-Based Care: Part Two | Better Care Network en The Benefits of a Cluster Approach to Supporting Foster Families | Better Care Network](#) (videos, 2019) on experiences with foster care for children with disabilities in Cambodia.
- [We All Need Families at the End of the Day - Special Care | Better Care Network](#) (video, 2015) on experiences with foster care for children with disabilities in Ghana.

### De-institutionalization processes of institutions for children with disabilities

- [Good practice guide of Hope and Homes \(2021\)](#) with a step-by-step plan for the reintegration of children with disabilities into their family.
- [Operational Guidance](#) on the reintegration of children with disabilities into their family.
- [Case study \(2022\)](#) on the reintegration of children with disabilities in Haiti.
- [Case study \(2022\)](#) on the reintegration of children with disabilities in Rwanda.
- [Case study and videos \(2023\)](#) on reintegration of children with disabilities in Rwanda.





### Quality criteria for projects for children with disabilities

Every country and situation is different. It makes a big difference whether you support children in their home situation, offer day care or, for example, offer education. However, there are a couple of basic conditions that apply to providing good care to children with disabilities:

- The staff and volunteers have knowledge of, and experience with the relevant disabilities and communication.
- There is sufficient staff for constant and stable care and interaction.
- The environment is accessible and safe and there are enough adaptations and aids available.
- There is a good [child protection policy](#) (in Dutch).
- A focus on integration of children, rather than family and community segregation.

### Tips?

Do you have tips or additions? Or questions about the care you provide? We would love to hear from you and think along if desired. You can contact us via [info@bettercarenetwork.nl](mailto:info@bettercarenetwork.nl)

*This overview was co-created by Angeliq Kester ([Liliane Fonds](#)), Florence Koenderink ([Family-Based Solutions](#)), Eric Bloemkolk ([Soft Tulip](#)), Kirsten Giethoorn ([Friendship Foundation](#)) and Lieke Scheewe ([DCDD](#)).*

### Do you want to know more?

Website:  
[www.bettercarenetwork.nl](http://www.bettercarenetwork.nl)

Email:  
[info@bettercarenetwork.nl](mailto:info@bettercarenetwork.nl)