

Disability Inclusion Helpdesk Report No: 140

Query	Evidence Review on Deinstitutionalisation of Children with Disabilities
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Date	28 th February 2025
Query	<ul style="list-style-type: none"> > Which OPDs work in the space, what do they specifically advocate for? Who is supporting them (e.g. any major donors, INGOs, foundations etc.)? > Which of the lead multilaterals beyond UNICEF are active, and in which regions and themes? Do they have a more targeted approach to deinstitutionalising children with disabilities? > What are the barriers to providing family-based or kinship-based care for children with disabilities (beyond stigma, deep-seated beliefs and assumptions and inadequate support for families and communities). How do these barriers vary in different countries and geographies. > What evidence is there on successful de-institutionalisation of children with disabilities – where has it been done well and sustainably? What were the key elements of success? How strong is this evidence and what are the gaps?
Enquirer	Gender and Equalities Department

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Acronyms

AU	African Union
CRC	Committee on the Rights of the Child
CRPD	Committee on the Rights of Persons with Disabilities
EU	European Union
FCDO	Foreign, Commonwealth & Development Office
NGO	Non-Governmental Organisation
OPD	Organization of Persons with Disabilities
WHO	World Health Organization
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children’s Fund

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“Institutionalization can never be considered as a form of protection of children with disabilities. All forms of institutionalization of children with disabilities – that is, placement in any non-family setting – constitute a form of segregation, are harmful and violate the Convention. Children with disabilities, like all children, have the right to family life and a need to live and to grow up with a family in the community.” – Committee on the Rights of Persons with Disabilities

Introduction

Creating a society where all children, including those with disabilities, have equal access and opportunities in all spheres of life means breaking down barriers, promoting values around diversity and accessibility, and ensuring respect of human rights. This includes as related to children’s care, within their own families and within alternative care systems. The purpose of the report that follows is to provide a review of evidence around family care for children with disabilities and the progress of deinstitutionalisation efforts around the world. The review was requested by the Foreign, Commonwealth & Development Office (FCDO) with an aim to respond to the following key questions:

- > Which organisations of people with disabilities (OPD) work in the space, what do they specifically advocate for? Who is supporting them (e.g. any major donors, international non-governmental organisations (NGO), foundations etc.)?
- > Which of the lead multilaterals beyond UNICEF are active, and in which regions and themes? Do they have a more targeted approach to deinstitutionalising children with disabilities?
- > What are the barriers to providing family-based or kinship-based care for children with disabilities (beyond stigma, deep-seated beliefs and assumptions and inadequate support for families and communities)? How do these barriers vary in different countries and geographies?
- > What evidence is there on successful de-institutionalisation of children with disabilities – where has it been done well and sustainably? What were the key elements of success? How strong is this evidence and what are the gaps?

The review of evidence was undertaken through a rapid process utilising the authors’ experience in care reform as the starting point alongside online searches using key terms linked to the questions laid out above. A snowballing approach was followed to bring in as much of the relevant literature as possible within the timeframe allocated. Literature which included the voice of young people with disabilities was prioritised. Whilst efforts were made to seek out literature from all regions, it should be noted that the majority of the review was focused on English-language publications. The contents of this report should not be considered an exhaustive review, but provides a reasonable overview.

Key terminology

There is often much debate around the different terminology related to the subject of alternative care for children, including the terms deinstitutionalisation, family-based alternative care and care reform. Different actors use different terms and sometimes mean different things by the same terms.

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This report will frame the evidence review through a care reform lens – this brings together three areas of change which are needed to ensure that all children can be cared for in safe and loving families. These are: 1) the increased provision of family support to strengthen the capacity of families (biological, extended, adoptive and alternative) to provide safe and nurturing care; 2) the increased provision of a range of family-based alternative care options for children who cannot, even temporarily, remain safely in the care of their families; and 3) the gradual ending of residential forms of alternative care, including larger institutions. By framing the review in this manner, deinstitutionalisation is considered alongside the need to strengthen family care and support, which are critical components of a safe and nurturing system of care for children. This framing is gaining increasing acceptance as key organisations¹ working in the sector learn from country care reform demonstrations.

This review will use the following definitions:²

Alternative Care: A formal or informal arrangement whereby a child is looked after at least overnight outside the parental home, either by decision of a judicial or administrative authority or duly accredited body, or at the initiative of the child, his/her parent(s) or primary caregivers, or spontaneously by a care provider in the absence of parents. Alternative care can be in a family-based, community-based, or residential setting.

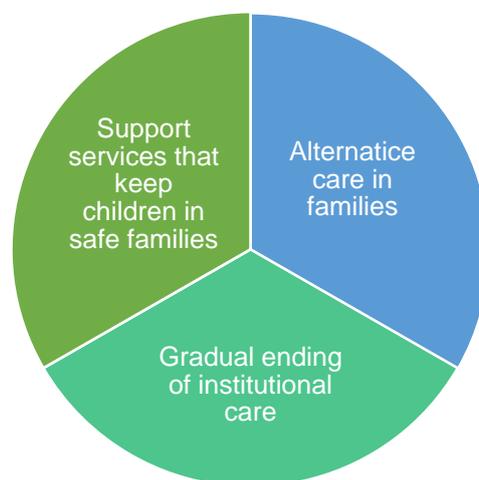
Care Reform: Changes to the systems and mechanisms that promote and strengthen the capacity of families and communities to care for their children, address the care and protection needs of vulnerable or at-risk children to prevent separation from their families, decrease reliance on residential care and promote reintegration of children and ensure appropriate family-based alternative care options are available³

Deinstitutionalisation: The process of transforming the alternative care system away from using residential care institutions to providing family-based care and services within the community. It involves all types of efforts to return the child or adolescent to family care or, where that is not possible or in their best interests, to provide them with family-based alternative care.

Institutional / Residential Care: The short-term or long-term placement of a child into any non-family-based care situation. Other similar terms include residential care, group care, and orphanage.

Family-Based Alternative Care: The short-term or long-term placement of a child into a family environment, with at least one consistent parental caregiver, a nurturing family environment where children are part of supportive kin and community. Includes kinship care, foster care, Kafalaah,

Care reform includes:



¹ Key initiatives and organisations using this framing include Transforming Children’s Care Collaborative, Changing the Way We Care, Maestral International, Hope and Homes for Children, Lumos, Better Care Network and others.

² Unless otherwise noted, definitions are sourced from Better Care Network. Glossary of Key Terms. Accessed at: <https://bettercarenetwork.org/glossary-of-key-terms>

³ Better Care Network and the Global Social Service Workforce Alliance. (2015). *The role of social service workforce development in care reform*. New York, USA: Better Care Network. P. 47. Available at: https://bettercarenetwork.org/sites/default/files/The%20Role%20of%20Social%20Service%20Workforce%20Development%20in%20Care%20Reform_0.pdf.

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guardianship and other models.

In addition, it is recognised that terminology around disability is also contested or not well understood. This review is based on the following understanding of these terms:

Disability:⁴ Persons with a disability include those who have long- term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Organisations of persons with disabilities:⁵ Organizations of persons with disabilities (OPD) are any organizations or associations led, directed and governed by persons with disabilities that are committed to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and fully respect the principles and rights affirmed therein. Some OPDs represent persons with all impairment types, while others may focus on a particular impairment type, gender or sectoral issue. They may represent persons in a particular geographical area or belonging to an international or national network. OPDs are distinguished from organisations for persons with disabilities, which can include (development) organisations that have a specific disability focus.

Summary of the harms children with disabilities face in residential care

The current movement to reform children's care systems globally has a strong focus on children with disabilities and ensuring inclusion. This has come about through significant advocacy from OPDs, care reform advocates, child protection experts, and care agencies campaigning for children with disabilities to be at the centre of care reform, and based on the evidence showing children with disabilities are at particular risk in residential care and have often been left out of deinstitutionalisation and transformation. The current movement is now building on the learning from care reform demonstrations and initiatives around the world.

Children with disabilities continue to be institutionalised in many countries and regions across high-, middle- and low-income countries and are over-represented within this form of alternative care as compared with their peers.⁶ Globally, it is estimated that one in three children in any given institution is a child with disabilities,⁷ although there are many challenges in measuring prevalence of institutionalisation and disability and data in many locations is missing or incomplete.⁸ In some regions, estimates of the likelihood of a child with disabilities being institutionalised are as high as 17 times more likely than those without disabilities.⁹ This number may be higher in countries where boarding schools and residential

⁴ UNCRPD as cited in Changing the Way We Care. (2021). Toolkit for Disability Inclusion in Care Reform: Disability terminology and resources.

⁵<https://www.unicef.org/media/124216/file/Engaging%20with%20organizations%20of%20persons%20with%20disabilities%20in%20humanitarian%20action.pdf>

⁶ Petrowski, N, C Cappa, and P Gross, 'Estimating the Number of Children in Formal Alternative Care: Challenges and results', Child Abuse & Neglect, vol. 70, 2017, pp. 388–398. doi:10.1016/j. chiabu.2016.11.026; UNICEF (2022) UNICEF factsheet on children with disabilities.

<https://www.unicef.org/media/128976/file/UNICEF%20Fact%20Sheet%20-%20Children%20with%20Disabilities.pdf>

⁷ Committee on the Rights of the Child, 'United Nations Global Study on Children Deprived of Liberty', Office of the United Nations High Commissioner, Geneva, 2019,

⁸ Every Child & Better Care Network (2012) Enabling Reform: Why supporting children with disabilities must be at the heart of successful child care reform. <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/enabling-reform-why-supporting-children-with-disabilities-must-be-at-the-heart-of-successful-child>

⁹ UNICEF Europe and Central Asia. (n.d.). Children with Disabilities'. <https://www.unicef.org/eca/children-disabilities>;

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health care facilities are not included in the data on alternative care.¹⁰

It is widely accepted that institutional care is harmful to children's development especially their physical growth, cognition, and attention, as well as their ability to form attachments and healthy social relationships throughout life.¹¹ Harms can be exacerbated by developmental delays and disabilities.¹² Adverse childhood experiences and trauma, including that caused by separation from family and institutionalisation, can itself, cause irreparable harm and delays in development.¹³ These harms continue to have a life-long impact.¹⁴ Children with disabilities are more likely to be at risk of harm, including abuse and neglect, within residential settings where child to caregiver ratios, caregiver capacity, specialised equipment and other resources may be limited.

Children with disabilities often spend longer in residential care than their peers and are leaving care as adults – or at times are remaining in institutions into adulthood.¹⁵ They are also likely to experience more changes of placements, moving between residential care providers, which is known to be destabilising and harmful.¹⁶ Within residential care settings children with disabilities are often segregated from other children and provided with limited support, even though they often need more support.¹⁷ What support is provided is often not specialised for their unique needs due to limited understanding of disability and limited use of case management approaches amongst child protection professionals, as well as overall limitations on time and resourcing.¹⁸ Children in residential care may have little or no contact with the outside world and minimal opportunities to participate in every-day activities, such as going cooking, shopping, or going out with friends, which limits the development of key life-skills.¹⁹ In addition, residential settings are often far away from family, especially if specialised care is limited in availability close to the community, and this distance reduces contact between a child and their family and community, which can be a mitigating factor in the negative impact of residential care on children.

¹⁰ UNICEF Regional Office for Europe and Central Asia. (2024). *TransMONEE Analytical Series. Pathways to better protection. Taking stock of the situation of children in alternative care in Europe and Central Asia*. Switzerland: UNICEF. [https://www.unicef.org/eca/media/33251/file/Pathways to better protection.pdf](https://www.unicef.org/eca/media/33251/file/Pathways%20to%20better%20protection.pdf).

¹¹ van IJzendoorn, MH. *et al.* (2020). Institutionalisation and deinstitutionalisation of children 1: a systematic and integrative review of evidence regarding effects on development, *The Lancet Psychiatry*, 7(8).

[https://doi.org/10.1016/S2215-0366\(19\)30399-2](https://doi.org/10.1016/S2215-0366(19)30399-2)[https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(19\)30399-2/abstract](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(19)30399-2/abstract); Lumos (2020). Invisible Children Visible Harms: The Scale And Effects Of Child Institutionalisation <https://www.wearelumos.org/resources/invisible-children-visible-harms/>

¹² Fernández L, Rubini A, Soriano JM, Aldás-Manzano J, Blesa J. (2020). Anthropometric Assessment of Nepali Children Institutionalized in Orphanages. *Children (Basel)*, 7(11). doi: 10.3390/children7110217.

¹³ Center on the Developing Child at Harvard University. (2018). ACEs and Toxic Stress. Accessed at:

<https://developingchild.harvard.edu/resources/infographics/aces-and-toxic-stress-frequently-asked-questions/>

¹⁴ Sand, H *et al.* (2024) 'Raised in conditions of psychosocial deprivation: Effects of infant institutionalization on early development', *Children and Youth Services Review*, 163. <https://doi.org/10.1016/j.chilyouth.2024.107718>

¹⁵ Changing the Way We Care (CTWWC) (2022). CTWWC Learning Brief: Disability inclusion in care reform. https://bettercarenetwork.org/sites/default/files/2023-03/430.011learningbrief_disability_inclusion.pdf; UNICEF (2022).

op cit.

¹⁶ Alves, S., Lucas Casanova, M., Sanches-Ferreira, M. *et al.* (2025). A Systematic Review of Residential Care for Children and Young People with Disabilities: Towards the Development of Quality Indicators. *Child Indicators Research* 18, 241–271 <https://doi.org/10.1007/s12187-024-10187-6>

¹⁷ van IJzendoorn *et al.* (2020). *op cit*; The European Network on Independent Living. (2013). Study on Deinstitutionalization of Children and Adults with Disabilities in Europe and Eurasia. <https://enil.eu/wp-content/uploads/2022/03/Study-on-Deinstitutionalization-of-Children-and-Adults-with-Disabilities-in-Europe-and-Eurasia.pdf>

¹⁸ van IJzendoorn *et al.* (2020). *op cit.*

¹⁹ The European Network on Independent Living (2013). *op cit.*

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In many places there remains a perception that children will access better care, education, health care and disability support in residential care settings. This is often fuelled by a view of disability through the “medical model” which promotes the idea that disability requires treatment and treatment requires institutionalization. Children with disabilities may be especially vulnerable to being placed in residential care during emergencies as families fleeing violence leave behind children with disabilities, especially if their agility makes it more difficult.²⁰

Finally, there are many challenges in building a robust evidence base on outcomes for children with disabilities in alternative care – both residential and family-based. Much of the evidence is WEIRD²¹ (Western, Educated, Industrialized, Rich, and Democratic)²² and faces ethical challenges around comparison groups and safe participation.²³ In much of the evidence, children with disabilities have been selected out of samples as disability is seen as a compounding problem which is hard to disentangle from the effects being measured. As noted by the authors of the Lancet Commission in relation to establishing the adverse effects of institutionalisation and their confounding with pre-existing risk factors or child characteristics, including disability: “Doubts about causes that are inferred on the basis of an observed association are likely to persist, and statistically controlling confounding differences between exposed and unexposed individuals cannot fully resolve these doubts.”²⁴ A recent publication from one of the very few longitudinal studies available, Pathways of Care Longitudinal Study in Australia, revealed that “children with disabilities have poorer wellbeing than children without disabilities across the three domains of physical health, socio-emotional wellbeing, and cognitive ability. However, children with disabilities have fewer difficulties at school and better school bonding.”²⁵ This study included a range of alternative care placements: kinship care, foster care, guardianship and residential care, as well as reintegration with parents and adoption. It was noted there was little or limited association between the placement type and the wellbeing of children with disabilities, and therefore the conclusion was that lower levels of wellbeing were driven mainly by children’s disability status rather than care factors.²⁶

²⁰ Save the Children, 2010. *Misguided Kindness*. <https://resourcecentre.savethechildren.net/document/misguided-kindness-making-right-decisions-children-emergencies/>

²¹ Based on Joseph Henrich’s work, the WEIRD acronym aims to highlight that much research has a bias towards one particular part of human society. For further information see: <https://www.apa.org/monitor/2010/05/weird> and <https://weirdpeople.fas.harvard.edu/qa-weird>

²² For instance, a recently published systematic review looking at residential care for children with disabilities mostly included studies from Europe and North America, only finding two studies from Asia (India and Japan) and none from Latin America, Africa and the Middle East. See: Alves, S., Lucas Casanova, M., Sanches-Ferreira, M. *et al.* (2025). A Systematic Review of Residential Care for Children and Young People with Disabilities: Towards the Development of Quality Indicators. *Child Indicators Research* 18, 241–271 <https://doi.org/10.1007/s12187-024-10187-6>

²³ van IJzendoorn *et al.* (2020). *op cit.*

²⁴ van IJzendoorn *et al.* (2020). *op cit.*

²⁵ Cheng, Z., Tani, M., Katz, I. (2023). Outcomes for children with disability in out-of-home care: Evidence from the pathways of care longitudinal study in Australia, *Child Abuse & Neglect*, 143. <https://doi.org/10.1016/j.chiabu.2023.106246>

²⁶ Cheng, Z. *et al.* (2023). *op cit*

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Stakeholder Mapping

There are hundreds of organisations, of all sizes, working in the disability rights space. They include networks, coalitions, large and small non-governmental organisations, community-based organisations, and direct service providers, who have a disability focus. Many of them focus on advocacy and others on service provision, including for inclusion and deinstitutionalisation of persons with disabilities. All of them work with and for persons with disabilities, however not all of them work on children's issues, nor are all of them organisations of persons with disabilities. Organisations of persons with disabilities are understood to be those led, directed and governed by persons with disabilities, or in the case of children, by parents and other caregivers of children with disabilities, that are committed to the UNCRPD and fully respect the principles and rights affirmed therein. They are some of the world's biggest advocates for change. Research for this paper, however, did not find any OPDs working directly in the care reform space in terms of direct services. In the words of Inclusion International, *"Institutions deny people basic rights of citizenship, personal control, privacy, decision-making and inclusion in the community. Millions of people, including children, live in institutions where they are at increased risks of disease, abuse and violence. Everyone has the right to choose where they live, and who they live with."*

OPDs working in deinstitutionalisation advocacy

Name of OPD	Advocacy priorities related to family care & deinstitutionalisation	Key Activities
<p><u>Inclusion International</u> An international network of people with intellectual disabilities and their families.</p>	<p>Focuses on high-level decision-makers such as UN bodies, ensuring that views and experiences of people with intellectual disabilities and their families are represented. Priority issues include inclusive education, closing institutions, inclusive employment and ending discrimination.</p>	<ul style="list-style-type: none"> > UN Advocacy > Resources > Member events > Working groups > Capacity building > Projects and programmes
<p><u>European Disability Forum</u> Network of member organisations with a mission of ensuring that decisions at European level concerning persons with disabilities are taken with and by persons with disabilities.</p>	<p>Works through channels to the European Parliament, the European Commission, and the Council of the EU. Supported research on the perspectives of Ukrainian children in institutional care and a rapid study of the situation of children in Ukraine, including those in institutions. Working on a demonstration of deinstitutionalization and transformation of children's institutions in Ukraine with Ukrainian Child Rights Network.</p>	<ul style="list-style-type: none"> > Campaigns > Research / evidence > Special projects > Resource development > Events > Advocacy
<p><u>African Disability Forum</u> ADF is a continental forum to unify and amplify the voice of persons with disabilities, their families and organizations in Africa</p>	<p>Advocates for inclusion of disability issues in development programmes and projects across Africa. Advocates at forums including African Union (AU), Regional Economic Communities and conferences and regional meetings. Note: limited information on their engagement</p>	<ul style="list-style-type: none"> > Capacity building for DPOs > Awareness raising > Reports on the

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at national, regional and international levels, and to strengthen the capacity of organizations of persons with disabilities in Africa to promote the rights and inclusion of persons with disabilities and their families.	with child-specific issues	UNCRPD within African countries > Advisor to the AU
<u>Autism Europe</u> 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.	Advocates for the rights of autistic people before European institutions, monitor European laws and policies, and promote appropriate care, education, training, support, services, etc.	> Public awareness and information > Consultants to WHO, UN and Council of Europe > Triannual international congress > Publications
<u>European Network on Independent Living</u> A user-led network of disabled people, with members throughout Europe.	Advocates for Independent Living values, principles and practices, provision of personal assistance and other community supports and services, a barrier-free environment and adequate technical aids. Targeted to EU institutions, Council of Europe, intergovernmental bodies and national governments. Lead network in the European Coalition for Community Living, which works for social inclusion by promoting quality community-based services as an alternative to institutionalization. Member of The European Expert Group on the transition from institutional to community-based support.	> Awareness raising and information dissemination > Advocacy > Capacity building > Learning exchanges > Data collection
<u>International Disability Alliance</u>	Alliance of global, regional and national organisations of persons with disabilities, advocating at the UN and with governments for inclusive global environments. Supported development of the UN Guidelines on Deinstitutionalisation and the 2024 Committee on the Rights of the Child recommendations on children with disabilities.	> Capacity building in advocacy > Special events
<u>Global Coalition on Deinstitutionalization</u> a collection of eight of the leading international organizations of persons with disabilities and civil society organizations.	Made up of other networks including IDA, Inclusion International, TCI, ENIL, Validity, DRI, Centre for Human Rights – so a mix of OPDs and allies, formed in June 2021 with the objective of supporting persons with disabilities worldwide to participate in a process of developing international Guidelines on Deinstitutionalization, including in Emergencies, with the CRPD Committee.	> Guideline development
<u>Transforming Communities for Inclusion</u> A global organisation (40 countries) of persons with psychosocial disabilities envisioning a future in	Focus areas include access to justice, community inclusion, deinstitutionalization, gender and youth. Supported development of the UN Guidelines on Deinstitutionalisation and the 2024 Committee on the Rights of the Child recommendations on children with disabilities.	> Youth participation > Grants / fellowships > Events / meetings > Capacity building > Campaigns

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which all human rights and full freedoms of persons with psychosocial disabilities are realized.	> Resources
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Key allies and care reform expert organisations

Name of Organisation	Type of Organisation	Activities in support of family care & deinstitutionalisation
Validity	NGO	A small but specialised international non-governmental organization working with partners in six core countries in Central and Eastern Europe and in Africa. Offers specialist legal knowledge. Provides advocacy and legal support around guardianship, institutionalisation, exclusion of people with mental disabilities from their communities, and barriers to accessing services and supports were human rights issues. Part of a large community of NGOs and others that lobbied for disability rights: Including the right to the right to live independently and be included in the community – with services to provide support rather than being forced to live in institutions. Collaborator on the UN Guidelines on Deinstitutionalisation and the 2024 Committee on the Rights of the Child recommendations on children with disabilities.
Ekisa Ministries	NGO	Ekisa Ministries supports children with disabilities so they can thrive in families and communities. They envision a world where every child grows up in a family, celebrated and loved, despite his or her disability. Their vision sees the end of discrimination of children and adults living with disabilities and a day when no more children need institutionalized care. Ekisa empowers parents and families to best care for their children. They are training other NGOs and community-based organisations in disability stigma reduction mostly in East and Southern Africa.
Disability Rights International		DRI is committed to preventing the abuses that take place in institutions by promoting the full participation in society by people with disabilities. Through the <i>Global Campaign to End the Institutionalization of Children</i> , DRI has led the international effort to gain recognition that all children have a right to live and grow up with a family. DRI is one of the founding members of the <i>Global Coalition on Deinstitutionalization</i> , bringing together leading disability groups from around the world. One of DRI's core goals is to support and collaborate with activists abroad to enforce the right of all people with disabilities to take charge of their own lives and to contribute to matters of law and policy affecting them. DRI has helped create new disability-run and family run advocacy groups in Hungary, Georgia, Kosovo, Mexico, Serbia, Turkey, Ukraine and Albania. In Argentina and Peru, DRI helped some of the most well-established human rights organizations create disability rights programs for the first time.
Changing The Way We Care	Global Initiative	An initiative designed to promote safe, nurturing family care for children: those reunifying from residential care facilities or those at risk of child-family separation. This includes strengthening families and reforming national systems of care for children, including family reunification and reintegration, and development of alternative family-based care. CTWWC envisions a world where all children thrive in safe and nurturing families. CTWWC demonstrates care reform in Guatemala, Kenya, Moldova, India and Haiti.

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<u>Save the Children</u>	NGO	Save the Children is the world's first and leading independent children's organisation. They work to ensure vulnerable children survive, learn and are protected. Together with children, Save works with governments and international organisations to ensure children's rights are on the political agenda and systems are in place to protect and provide for all children.
<u>Able Child Africa</u>	Network/Alliance	For the last 40 years Able Child Africa has been part of a progressive change to support African organizations working to improve the lives of children with disabilities. As our reach has grown over the last ten years, we began a process to analyse what our role has been, what it is now and what it should be in the future. The network is made up of the leading African organizations who share a common vision of a 'world in which no child with a disability is left behind.' These are organizations who were founded in and are based in Africa, and who work specifically on improving the lives of children with disabilities. Together, we are working across Africa, breaking down barriers to inclusion so that children with disabilities are able to thrive.
<u>UBS Optimus Foundation</u>	Donor	Millions of children around the world are experiencing violence or are at risk of exploitation. Together we can put an end to this. At the UBS Optimus Foundation, we can help you maximize your impact in the area of child protection. Your contribution will focus on prevention as the most impactful place to intervene in child protection, investing across the continuum of public child protection systems, the broad range of community responses, and family support.
<u>Keystone International</u>	NGO	Keystone Human Services designs and implements culturally relevant community-based services and service systems that promote full inclusion and culturally valued roles. Through Special Consultative Status at the UN, we bring discussions of disability inclusive disaster response, deinstitutionalization, and advocacy for and with people with disability to a global stage, influencing decision-makers at the highest international level. We provide consultation and education around dismantling institutions and developing responsive, effective, and inclusive supports that help people move toward belonging, acceptance, and a rich community life. Supports people to live their best lives in the community. We are part of a global movement to support people with disabilities as they leave congregated, segregated settings and move into homes in the community full of meaningful opportunities to explore their interests, pursue their dreams, and achieve their goals.
<u>Lumos</u>	NGO	Lumos' mission is to realise every child's right to a family by transforming care systems around the world. All children grow up in safe and loving families within supported communities. They support governments, civil society and other influential organisations around the world so we can turn commitments to care reform change into action. By sharing our learning and expertise, we'll also support locally-led efforts that lead to lasting change and safe, quality care for vulnerable children.
<u>Hope and Homes for Children</u>	NGO	Hope and Homes for Children has been working to stop the institutionalisation of children around the world for decades. Working in multiple countries, inspiring organisations, including the UN, EU and governments around the world, to close the doors of orphanages and bring children back to family. Campaigns including #BackToFamily, #EndOrphanageTourism and Every Child Deserves a #HomeAdvantage

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<u>SOS Children Villages</u>	NGO	Working across 130 countries, SOS is the world's largest organization focused on ensuring that children and young people without parental care or at risk of losing it grow up with the care, relationships and support they need to become their strongest selves. Their programs span prevention to keep families together, protection by offering care when family is not in the best interest of the child, and policy and practice advocacy.
USAID – Center of Excellence on Children in Adversity (<i>webpage currently unavailable</i>)	Donor	This office of the United States Agency for International Development comes under the Inclusive Development Hub and oversees programs for children in need in alignment with the U.S. Government's Action Plan on Children in Adversity, which includes early childhood, prevention of violence against children, and family care. USAID has been a donor to inclusive care reform efforts for decades across all regions of the world. <i>Programmes are currently on hold.</i>
<u>Special Olympics</u>	NGO	A 50+ year old organisation started out of the desire to see institutionalisation and family separation of children with disabilities end. Special Olympics works all over the world, including advocating for, researching and promoting inclusive education, an important program for decreasing reliance on institutional care. Partners with care reform actors in countries around the world.
<u>EuroChild</u>	Network/Alliance	A 200+, 42 country network of organisations and individuals working with and for children in Europe. Activities include influencing policies, building civil society capacity, facilitating mutual learning and exchanging practice and research. The network is committed to fostering participation of children and families. EuroChild works closely with the EU and the European Expert Group on the Transition from Institutional to Community-Based Care, amongst others.
<u>Martin James Foundation</u>	Donor	A global network of organisations working in family-based alternative care for children and believing that children should grow up in safe and loving families. Makes small grants to organisations working in care reform, including for specialised disability inclusive family-based alternatives.
<u>Global Coalition on Deinstitutionalization</u>	Network/Alliance	Made up of other networks including IDA, Inclusion International, TCI, ENIL, Validity, DRI, Centre for Human Rights, etc. GC-DI was formed in June 2021 with the objective of supporting persons with disabilities worldwide to participate in a process of developing international Guidelines on Deinstitutionalization, including in Emergencies, by the CRPD Committee.
<u>Women Enabled</u>	Network/Alliance	Women Enabled International contributed to the CRC Committee's general discussion on Children's Rights and Alternative Care. This submission focuses on the intersection of gender and disability for institutionalized girls and gender non-confirming children with disabilities and presents an overview of the common rights violations they face. While the ultimate goal is deinstitutionalization so girls with disabilities can live grow up in a family and fully realize their rights, States must ensure that the rights of girls with disabilities are respected, protected, and fulfilled everywhere, including while institutionalized.
<u>Humanity and Inclusion</u>	NGO	Supports humanitarian emergencies, crisis and longer-term development with a focus on disability – operate projects with and for people with disabilities focused on inclusion, inclusive emergency response, and reducing impact of conflict. Includes projects on inclusive education, education for girls with

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		disabilities, parent support, public awareness and stigma reduction.
<u>Family for Every Child / Change Makers for Children</u>	Network / Alliance	<p>A global alliance of local organisations working on the front line with children and families in need. Activities include direct support, research, knowledge exchange, humanitarian responses and campaigns for rights.</p> <p>Change Makers for Children is an open, collaborative, global movement of people working in local civil society to improve the lives of children and families worldwide. The platform is hosted by Family for Every Child. A disability community of practice developed the following toolkit for families and practitioners.</p>
<u>Better Care Network / Transforming Children's Care Global Collaborative Platform</u>	Network / Alliance	<p>The mission of the BCN is to facilitate active information exchange and collaboration on the issue of children without adequate family care and advocate for technically sound policy and programmatic action on global, regional, and national levels. Building on joint efforts advocating for the 2019 UNGA Resolution and the Key Recommendations, and clear interest expressed by a broad group of actors to strengthen sectoral cooperation and collaboration, they established the Transforming Children's Care Collaborative. The overall vision for the collaborative platform is to establish more strategic sector-wide collaboration spanning the global to the local level and inclusive of a wider range of stakeholders. The collaborative hosts a disability community of practice.</p>
<u>The European Expert Group on the transition from institutional to community-based support</u>	Network / Alliance	<p>A coalition advocating to replace institutionalisation with family- and community-based support representing, amongst others, children and their families.</p>

Multilateral organisations supporting care reform and deinstitutionalisation of children

The **Committee on the Rights of Persons with Disabilities** (CRPD) is an 18-member body of independent experts which monitors implementation of the UNCRPD by the States parties. All States parties submit regular reports to the CRPD on how the rights enshrined in the Convention are being implemented. States must report initially within two years of ratifying the Convention and, thereafter, every four years. The Committee examines each report and makes recommendations to strengthen the implementation of the Convention in that State. It forwards these recommendations, in the form of concluding observations, to the State party concerned. Amongst other things the CRPD adopted "Guidelines on Deinstitutionalization, including in Emergencies" in 2022, essentially outlining standards for countries to follow when transitioning people with disabilities away from institutional care and into community living environments, including children. That same year, jointly with the Committee on the Rights of the Child (CRC), they released a joint statement to strengthen the protection of the rights of children with disabilities, and provide guidance for Member States in the adoption of laws and policies consistent with a human rights approach to disability. Both Committees call for targeted strategies and action plans for

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deinstitutionalisation and the end of institutionalisation of children with disabilities.²⁷

UNICEF strives to create a world where children with disabilities can reach their full potential by promoting a social and human rights–based approach to disability. Recognizing that unaccommodating environments and attitudes create barriers, UNICEF advocates for accessibility, inclusive policies, and community-based services that provide disability-specific support. Their work includes building evidence, supporting caregivers, training frontline workers, combating stigma, and amplifying the voices of children with disabilities to ensure they can fully participate in society. UNICEF works closely with host government and non-government partners to improve child protection and care systems, including ensuring inclusion of children with disabilities. UNICEF is leading several efforts linked to the measurement of care reform and disability. Firstly, a toolkit has been made available to guide the collection of data on children in residential care.²⁸ The package is designed to generate information on the number and location of all residential care facilities in a country, the number and basic characteristics of children living in them, as well as selected measures of their well-being. This includes gathering data on children with disabilities through the UNICEF/Washington Group Child Functioning Module which is built into the second phase of data collection.²⁹ Whilst there are challenges with using the Child Functioning Modules within residential care settings, it is important for this approach to be more widely tested so that data collection on children in residential care can be standardised with approaches recommended for family-based data collection.³⁰ Secondly, a recently launched exercise to develop a statistical classification for alternative care was approved by the UN Statistical Commission and is being led by UNICEF.³¹ This work is currently underway and will include guidance on classifications of type of care and necessary disaggregation categories, including disability. The aim of this exercise is to promote a standardised approach to collecting and classifying statistical data regarding alternative care for children which can be used to align national and international data collection exercises, especially administrative data, household surveys and censuses.

World Health Organisation (WHO) developed a tool and disability disaggregation instrument for integrating functioning and disability into national census and demographic health surveys. Their Child Health and Development Unit focuses on programmes and investments in the healthy development of children. The Nurturing Care Framework is a roadmap for helping children survey and thrive. It includes key message and recommendations on services for strengthening families. Recommendations for deinstitutionalization published in 2014 suggest five principles for deinstitutionalization were identified: community-based services must be in place; the health workforce must be committed to change; political support at the highest and broadest levels is crucial; timing is key; and additional financial resources are needed.³² The WHO has also supported initiatives around strengthening families including: INSPIRE Strategies for Ending Violence

²⁷ EuroChild. (2022). UN Committees Reaffirm Human-Rights Model for Children with Disabilities. Accessed at: <https://eurochild.org/news/un-committees-reaffirm-human-rights-model-for-children-with-disabilities/#:~:text=UN%20Committees%20reaffirm%20human%2Drights,relation%20to%20children%20with%20disabilities>.

²⁸ See: <https://data.unicef.org/resources/data-collection-protocol-on-children-in-residential-care/>

²⁹ UNICEF (2022.) Protocol for a National Census and Survey on Children in Residential Care. <https://data.unicef.org/resources/data-collection-protocol-on-children-in-residential-care/>

³⁰ Zia, N. *et al* (2023). *op cit*.

³¹ UNESCO Statistical Commission, Committee of Experts on International Statistical Classifications, 55th Session, E/CN.3/2024/21. https://unstats.un.org/UNSDWebsite/statcom/session_55/documents/2024-21-Classifications-E.pdf

³² World Health Organization. (2014). Innovation in Deinstitutionalization. https://iris.who.int/bitstream/handle/10665/112829/9789241506816_eng.pdf?sequence=1

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Against Children and Parenting for Lifelong Health, and open access parenting programme (which has been adapted for families reintegrating children from institutions).³³

European Union (EU) has been promoting the transition from institutional to family- and community-based care through EU policy and funds since more than a decade. Although the EU thus highly encourages its Member States to focus on providing community-based alternative care, early intervention, preventative measures and family strengthening, more should be done to share good practices or guidance available and which measures, services and systems can contribute to this goal. Grant mechanisms support projects for disability inclusion, deinstitutionalisation, and care reform in the EU member countries and beyond. For example, EU funds DPO Autism Europe and a project in Jordan to support the country's national strategy for deinstitutionalisation of persons with disabilities, including children.³⁴ The European Child Guarantee, promoted by the European Council establishing measures to help lift children out of poverty and social exclusion. Children with disabilities, children outside of family care, and other disadvantaged children are targeted to break the cycle of vulnerability. The Child Guarantee is an important tool in keeping children in and returning them to families out of institutions.³⁵

World Bank is supporting inclusive education for children with disabilities through their lending projects, advisory activities and analytical work in countries like Vietnam, Moldova, Malawi and India. Moldova's care reform has gone hand-in-hand with reform of the education system and inclusive schools have been critical to deinstitutionalization. The World Bank program, Integration of Children with Disabilities into Mainstream Schools helps districts to plan for and implement strategic inclusion strategies.³⁶ Programs and investment in the early years have also been working to integrate the most vulnerable children, including those with disabilities and at-risk for institutionalisation.

Global Disability Fund³⁷ is a unique partnership that brings together UN entities, governments, OPDs and broader civil society to advance the rights of persons with disabilities around the world. It was established by a subset of members of the IASG-CRPD in 2011. The Partnership was created to foster collaboration between its members and complement their work around disability inclusion through UN Joint programming. Programs include many for reducing discrimination against children with disabilities, promoting access to services, advancing child rights, and more – all which address the barriers to family care for children with disabilities.

³³ World Health Organization. Parenting for Lifelong Health. <https://www.who.int/teams/social-determinants-of-health/parenting-for-lifelong-health>

³⁴ Described at: <https://inclusion-international.org/programme/de-institutionalisation-reform-and-economic-empowerment-of-vulnerable-jordanians/>

³⁵ EU Alliance for Investing in Children. (2021). European Child Guarantee Prioritises Children in Alternative Care. https://deinstitutionalisation.com/wp-content/uploads/2021/07/child-guarantee_eeg-reaction_final-3.pdf

³⁶ More information: <https://www.worldbank.org/en/news/feature/2017/11/30/learning-for-all-must-include-children-with-disabilities#:~:text=The%20World%20Bank%20has%20also,and%20capacity%20across%20the%20region.>

³⁷ More information: <https://unprpd.org/about-us/>

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Barriers to Family Care for Children with Disabilities

Global trends and barriers

Although progress is being made with care reform in many locations and contexts there continues to be challenges to the full inclusion of children with disabilities in these processes. This is due to the layering of social and structural barriers faced by these children and their families with the challenges of ensuring adequate access to family support services and family-based alternative care, as well as safe and gradual deinstitutionalisation – including reintegration of children with families and transformation or closure of institutions. As young people age out of the care system, it is also important to consider the linkages of deinstitutionalisation to support for adults with disabilities. As noted in a disability inclusion toolkit by the global initiative, Changing the Way We Care, the main barrier to care reform for children with disabilities comes because it “is often more time and resource intensive and requires input from a broader range of community members, service providers and others as compared to children without disabilities.”³⁸

Specifically, the evidence that was reviewed highlighted the following challenges:

National system level

- > **Requires an inclusive strategy:** Driving a system-wide change in the way family care is supported and provided for children with disabilities required the national government to lead a coordinated approach across sectors and actors. A national care reform strategy and coordination body is critical in guiding the reform process. This strategy needs to have a central focus on children with disabilities so that as the inclusive approaches are taken to strengthening the capacity of services, workforce and data systems from the very beginning. However, the strategy must also recognise that even with this focus from the beginning it is likely that children with disabilities will be the last ones left in residential care (as seen in Rwanda and Eastern Europe) and so the strategy will need to also consider how to improve the quality of residential care, which can be seen as counter-productive to the overall aim of a care reform strategy.³⁹
- > **Laws and policies need to be inclusive:** It is important that any care reform strategy is backed up by conducive child protection and disability laws and normative frameworks. It is important that both child and disability focused legislation promotes family care for children and deprioritises institutionalisation for children and adults.
- > **Investment in participation of children and young people with disabilities:** The perspectives of children and young people should be included in developing national care reform strategies, including those with disabilities. This requires investment in making opportunities for their engagement to be inclusive.⁴⁰
- > **Care reform takes a long time:** Systems change requires a commitment for a long period of time. This is particularly true when taking a disability inclusive approach as this requires the

³⁸ Changing the Way We Care. (2021). CTWWC Toolkit for Disability Inclusion: Reunification and reintegration of children with disabilities into family care. https://bettercarenetwork.org/sites/default/files/2023-05/reunification_and_reintegration_of_children_with_disabilities_into_family_care.pdf

³⁹ McCall RB. (2013). The consequences of early institutionalization: can institutions be improved? - should they? *Child and Adolescent Mental Health*, 18(4):193-201. DOI: 10.1111/camh.12025.

⁴⁰ Kenya Society of Care Leavers (KESCA) & CTWWC (2018). How to Engage Care Leavers in Care Reform <https://kesca.org/resources/>

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development of specialised family care and support policies, guidelines, services and workforce nationally and sub-nationally.

- > **Resource intensiveness:** Building and sustaining inclusive approaches and specialised family care and support will be more resource intensive. Many care systems include a mix of funding sources which need to be coordinated and directed towards reform efforts and yet some sources of funding are not immediately visible or are hard to regulate. However, it is well-established that the cost of residential care is higher than for family care, even for children with disabilities.⁴¹
- > **Cross-sector collaboration:** Advocacy, policies and services need to be aligned between child protection and disability sectors. This requires the issue of care reform to be a priority agenda item for both and for actors to pull in the same direction.
- > **Definitions and data:** Much of the evidence around care reform simply does not include children with disabilities or because different definitions and measurement approaches are used they are likely to be overlooked or undercounted. Data on children with disabilities in care reform needs to be “consistent and comprehensive while also being child focused, recognising that disability status can change and that children’s privacy and rights to self-identify as having a disability should be respected.”⁴² A UK study highlighted that “to ensure that the rights of disabled children in state care are identified, acknowledged and upheld, ‘being counted’ is a fundamental first step.”⁴³ This requires agreement on approaches to measurement which cannot just be based on a diagnosis, especially where opportunities for assessments are limited or too focused on a medical approach without consideration for self-identification.⁴⁴ Where children with disabilities are included it can reveal significant differences in care pathways and well-being outcomes, as shown in recently published studies from Australia⁴⁵ and Guatemala, Kenya and Moldova.⁴⁶

Local service provision level

- > **Availability, flexibility and coordination of support services:** Health, rehabilitation, education, social protection and recreation services for children with disabilities are limited, inaccessible or too rigid in many places, leaving families to struggle without adequate

⁴¹ Browne, K. (2005). A European Survey of the Number and Characteristics of Children Less than Three Years Old in Residential Care at Risk of Harm. *Adoption & Fostering*, 29(4), 23-33. <https://doi.org/10.1177/030857590502900405>;

Hernández, MA. (2023) Children Shut Away: Disability Rights in Guatemala. <https://djiip.org/children-shut-away-disability-rights-in-guatemala/>

⁴² Cheng, Z. *et al.* (2023). *op cit.*

⁴³ Hill, L., Baker, C., Kelly, B., and Dowling, S. (2017). Being counted? Examining the prevalence of looked-after disabled children and young people across the UK. *Child & Family Social Work*, 22. doi: [10.1111/cfs.12239](https://doi.org/10.1111/cfs.12239).

⁴⁴ Baker, C. & Briheim-Crookall, L. (2024). Disability, disparity and demand: Analysis of the numbers and experiences of children in care and care leavers with a disability or long- term health condition. Coram Voice.

https://www.coram.org.uk/wp-content/uploads/2024/10/Coram_Disability-Report.pdf; Zia, N., Ho, S., Wako, J., Wakia, J. & Bachani, AM. (2023). Disability measurement in residential care in Kenya and its role in case management. <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/disability-measurement-in-residential-care-facilities-in-kenya-and-its-role-within-case-management>

⁴⁵ Cheng, Z. *et al.* (2023). *op cit.*

⁴⁶ Wakia, J., Yekeye, I., Neville, SE. & Bradford, B. (2024) Year 5 Household Survey: Understanding Caregiver Protective Factors and Child Well-Being Amongst Families in Guatemala, Kenya and Moldova. CTWWC.

<https://bettercarenetwork.org/library/social-welfare-systems/data-and-monitoring-tools/year-5-household-survey-understanding-caregiver-protective-factors-and-child-well-being-amongst>

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support.⁴⁷ A study in the UK looking at experiences of care leavers heard from some support workers that because of limited availability of funding some young people were “not disabled enough” to be eligible for support services.⁴⁸ Ensuring children with disabilities can remain in/return to family care requires a range of services to be locally available and accessible under a coordinated approach with clear lines of communication.⁴⁹ Each child requires a clear multi-agency plan to support them in their care placement, in school and in the community.⁵⁰ This multi-agency support requires service providers to pull together to support family care, yet it is undermined when service providers believe children with disabilities should be placed in to residential care.⁵¹

- > **Availability and access to reintegration and family-based alternative care options:** Children with disabilities are often less likely to be considered for reintegration from residential care to their families or for placement in family-based care.⁵² This is linked to the limited support services available to families (see point above), the knowledge and skills of the workforce (see point below), as well as to a lack of foster care programmes specifically designed to build the capacity and provide the benefits needed for specialised foster care.⁵³
- > **Knowledge and skills of social service workers:** A case management approach has been shown to improve outcomes for children and families who are part of a child protection and care system. However, children with disabilities are often excluded from case management processes or their needs are not fully considered when the knowledge and skills that social service workers need are lacking.⁵⁴ This might be due to the design of the case management process and tools or the training and capacity of the workers in case management approaches.⁵⁵ Similarly, social service workers understanding of disability is often limited by the prevailing social norms and lack of training.⁵⁶ Social service workers can benefit from understanding the social model and to learn to look for strengths, needs and environmental factors at play for each child, which can change overtime.⁵⁷
- > **Gatekeeping mechanisms:** A key part of care reform is preventing children from entering in

⁴⁷ UNICEF ESARO. (2021). Children With Disabilities and Care Reform In Eastern And Southern Africa <https://www.unicef.org/esa/media/11021/file/Children-Disabilities-Care-Reform-ESA-2021.pdf>; EuroChild (2018). Childonomics: Measuring the long-term social and economic value of investing in children: Summary of findings. https://eurochild.org/uploads/2020/11/Childonomics_summary_of_findings_.pdf; Baker, C. & Briheim-Crookall, L. (2024). *op cit*

⁴⁸ Baker, C. & Briheim-Crookall, L. (2024). *op cit*

⁴⁹ Changing the Way We Care. (2022). *op cit*; Cheng, Z. *et al.* (2023). *op cit*; Erwin, D. (2023) Headphones, Odd Shoes & A Second Chance at Life Headphones, Odd Shoes & A Second Chance at Life An Exploration of the Experience of Children in Care & Care-leavers with Disabilities. Empowering People in Care (EPIC). <https://www.epiconline.ie/app/uploads/2024/03/Headphones-Odd-Shoes-A-Second-Chance-at-Life.pdf>

⁵⁰ Cheng, Z. *et al.* (2023). *op cit*.

⁵¹ Better Care Network, UNICEF, USAID, PEPFAR (2015). Making decisions for the better care of children. The role of gatekeeping in strengthening family-based care and reforming alternative care systems. <https://bettercarenetwork.org/sites/default/files/Making%20Decisions%20for%20the%20Better%20Care%20of%20Children.pdf>

⁵² Alves, S. *et al.* (2025). *op cit*.

⁵³ Changing the Way We Care. (2024). Good Practices of Foster Care for Children with Complex Needs: Findings from a Rapid Review of the Literature to Inform Programming in Moldova

⁵⁴ Sammon, EM. & Burchell, G. (2018). Family care for children with disabilities: practical guidance for frontline workers in low- and middle-income countries. World Learning, Partnerships for Every Child, & USAID. https://bettercarenetwork.org/sites/default/files/FamilyCareGuidance_508.pdf

⁵⁵ Changing the Way We Care. (2021). *op cit*.

⁵⁶ Erwin, D. (2023). *op cit*.

⁵⁷ Zia, N. *et al.* (2023). *op cit*; Cheng, Z. *et al.* (2023). *op cit*.

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care in the first place, a process known as ‘gatekeeping’. Gatekeeping mechanisms should be able to assess children’s and their families’ situation from an integrated perspective, to identify their strengths and needs and how these needs can be met by available services (see first point in this section). Efforts to prevent children with disabilities being unnecessarily separated from their families will be undermined where such gatekeeping mechanisms are missing, limited in their ability to review cases with a disability inclusive lens (perhaps because the right knowledges and skills are not present in the makeup of a multi-agency gatekeeping team) or not able to refer families to needed services.⁵⁸

- > **Small group homes:** There continues to be debate around the role of small group homes in a care reform process. Small group homes, where children live together with employed caregivers in a home-like setting, are a form of residential care that gained prominence in many places, especially in eastern Europe, as part of reducing reliance on large institutions. Whilst some argue these are “family-like” or “family-type” care settings, they can easily develop many of the same features as large institutions in terms of very structured routines, limited choice for children and changeover of caregivers.⁵⁹
- > **Stigma and service provision:** Lack of understanding and negative social norms around disability in the community and amongst the workforce (both social services as well as medical, education etc) can undermine early identification of congenital disability or a developmental delay and referrals to and provision of appropriate support.⁶⁰
- > **Referrals into adult social care and protection:** All children aging out of care when they reach adulthood face a challenging time of negotiating the transition from being a child in care to becoming an adult and living independently. Very often care and support services simply end when a young person turns eighteen. Where programmes do exist to support this transition, they are often limited in what they provide and who is eligible.⁶¹ Children with disabilities will face the same challenges in this transition as well as negotiating referrals into adult social protection programmes that allow them to live independently.⁶² In some contexts adult institutionalisation persists so that people with disabilities spend their life in institutions. In a UK study, young people with disabilities highlighted barriers they faced at this point of transition to include: processes being overly complex, failures in agencies to work well together, violations of rights to entitlements and disputes on the capacity a young person has, and not following person-centred approaches.⁶³

Child and family level

- > **Case management and plans:** Importance of case management to allow individual plans, building on children’s strength – requires a level of training and tools for workforce and an understanding of disability from the social model, which is limited in many places. Assessment of the child’s strengths and needs should be conducted regularly and work with the child should focus on strengthening the protective factors which are likely to support the child’s trajectory through the care system. Children’s needs change over time, so assessment should

⁵⁸ Better Care Network, UNICEF, USAID, PEPFAR. (2015). *op cit*.

⁵⁹ Ivanova, V. and Bogdanov, G. (2013). The Deinstitutionalization of Children in Bulgaria – The Role of the EU. *Social Policy & Administration*, 47: 199-217. <https://doi.org/10.1111/spol.12015>

⁶⁰ Sammon, EM. & Burchell, G. (2018). *op cit*; CTWWC (2022). *op cit*.

⁶¹ Alves, S. *et al.* (2025). *op cit*.

⁶² Baker, C. & Briheim-Crookall, L. (2024). *op cit*.

⁶³ Baker, C. & Briheim-Crookall, L. (2024). *op cit*.

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be ongoing.⁶⁴

- > **Integration of careleavers:** Care leavers with disabilities, especially those who age out of the care system, are often not well supported in their transition (see section above), and have limited knowledge and connections. This is seen to result in poorer outcomes compared to other care leavers. A recent study in the UK saw care leavers with disabilities reporting lower well-being on a range of measures e.g. they felt lonelier, less likely to feel safe or settled where they lived and more likely to report difficulties coping financially.⁶⁵
- > **Engagement in decision-making:** It is the right of children and young people to have a say in decisions that affect them and this includes decisions about the care. Yet the support to ensure this happens in a meaningful way is often missing.⁶⁶ Young people themselves are asking for better relationships with the professionals who they work with, requesting more emphasis on listening, explaining what is happening and following through.⁶⁷
- > **Stigma and families:** When caregivers and children experience negative attitudes due to the stigmatisation of disability in their communities can isolate families and stop caregivers from seeking support.⁶⁸ When children with disabilities are invisible and hidden away this is likely to delay identification of risks and prevent early intervention.⁶⁹
- > **Caregiver engagement:** When caregivers – both parents and foster or kinship carers – do not have a positive attitude, good understanding of and the skills needed to support children with disabilities this can prevent children from remaining or entering family care. Similarly, it's important that caregivers within residential care are supportive of the reintegration of children into families. In fact, it has been shown that they can play a proactive role in preparing children by providing high quality care leading to physical, cognitive, and socioemotional development of children with disabilities.⁷⁰

Geographic and contextual trends

Whilst global momentum has built around the need for care reform and the centrality of children with disabilities within this, it is difficult to look at variations between regions and countries. There are a lot of similarities in the barriers that children with disabilities and their families are facing and there is still not enough evidence to confidently identify differences across geographies. At the same time, there are also similarities around the trajectory and process of care reform. Below are some nuances that have been identified.

Progress in **Eastern Europe** is further ahead, simply because care reform began in earnest earlier than many other regions of the world and the danger of children with disabilities being left behind became apparent sooner. Accession to the EU has also promoted progress. Children protection efforts during the war in Ukraine has included a focus on deinstitutionalisation, both for children within Ukraine and those who are refugees in other countries, including building better systems of family strengthening and family-based alternative care.

In **Sub-Saharan Africa** there are some countries, such as Rwanda, who have begun care

⁶⁴ Cheng, Z. *et al.* (2023). *op cit.*

⁶⁵ Baker, C. & Briheim-Crookall, L. (2024). *op cit*

⁶⁶ van IJzendoorn *et al.* (2020). *op cit*

⁶⁷ Erwin, D. (2023). *op cit.*

⁶⁸ CTWWC (2022). *op cit.*

⁶⁹ Sammon, EM. & Burchell, G. (2018). *op cit.*

⁷⁰ McCall (2013). *op cit.*

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reform efforts decades ago and have similarly seen how children with disabilities can be left behind. Marginalisation of these children, combined with non-existent or insufficiently enforced legal protections and lack of services and are particularly common in resource-constrained settings, including many contexts in Africa.⁷¹ In Rwanda the challenges to reintegration of children with disabilities included lack of access to the necessary additional services, and the need for change in attitudes of both communities and parents, themselves.⁷² In both Rwanda and Kenya, engagement of National Councils for Persons with Disabilities proved critical. There has been a growing emphasis on sharing learning around care reform, including for children with disabilities through, for example, the UNICEF-Changing the Way We Care East and Southern Africa Regional Office Care Reform Learning Platform.⁷³

South and South-East Asia are home to more than half of the world's population. Many countries in the region are vulnerable to man-made, climate change-related and natural disasters including earthquakes, cyclones, storms, floods, rising sea levels, etc. In many countries, such as Myanmar, India, Laos and Cambodia internal migration for work is common. Children are affected when they are left behind by their migrating parents. Children are placed or remain in alternative care for interrelated reasons poverty, access to education, and migration of one or both parents. Furthermore, the natural disasters many countries in the region are prone to contribute to orphaning, displacement, separation and child trafficking. A phenomenon caused by *voluntourism* contributes to the later – documented instances find children trafficked into so-called *orphanages* where unknowing foreigners come to volunteer and donate funds.⁷⁴ Many countries are making progress on care reform. In India, the COVID-19 pandemic was an impetus for reconnecting children living in institutions with their families since government mandates required children be sent out of congregate care and, often, that facilities be closed. In 2021, the Government of India's *Mission Vatsalya* was passed as a roadmap for achieving the child protection priorities, including phasing out institutional care, providing increased support to families and developing family-based alternative care.⁷⁵

According to UNICEF,⁷⁶ across **Latin America and the Caribbean** millions are driven to leave their homes and communities by the conditions they face in their country of origin, poverty, the collapse of essential services, the threat of armed violence, or the devastating impact of extreme weather events. Sometimes children are left behind in residential institutions or in the care of relatives, especially those with disabilities. Lack of official documentation can make it hard to reunify these children. Just like the causes of separation and institutionalization, the root causes of migration are highly variable, from socioeconomic

⁷¹ UNICEF and Changing the Way We Care. (2021). Children with Disabilities and Care Reform in Eastern and Southern Africa. Accessed at: <https://www.unicef.org/esa/media/11021/file/Children-Disabilities-Care-Reform-ESA-2021.pdf>

⁷² Republic of Rwanda, National Commission for Children. (2019). Care Reform in Rwanda: Process and lessons learning 2012-2018. Accessed at: <https://www.unicef.org/rwanda/media/1646/file/Process-and-Lessons-Learnt-Care-Reform-2012-2018.pdf>

⁷³ See: <https://www.unicef.org/esa/learning-platform-care-reform>

⁷⁴ SOS. (2016). Alternative Child Care and Deinstitutionalisation in Asia. Accessed at: <https://www.sos-childrensvillages.org/getmedia/1b925bf1-5587-4f7f-976a-92293ddf09/Asia-Alternative-Child-Care-and-Deinstitutionalisation-Report.pdf>

⁷⁵ For more information see: <https://wcdhry.gov.in/mission-vatsalya/>

⁷⁶ UNICEF. (2025). Child Alert: Child migration in Latin America and the Caribbean. <https://www.unicef.org/child-alert/migration-latin-america-caribbean#:~:text=Millions%20of%20children%20and%20families,transit%20countries%20and%20their%20destinations.>

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factors like poverty, limited livelihood opportunities, structural inequality, food insecurity and barriers to essential services, to a desire among families to secure a more hopeful future for their children.

Safe and nurturing care can be challenging in the **Middle East and North Africa**, where UNICEF estimates 50 million children are in need of humanitarian assistance, 15.6 million people are refugees, and more than 16 million are displaced.⁷⁷ Being on the move, pervasive and ongoing conflicts, unstable governments, and poverty compound barriers like poverty and violence to family care. Children are exploited in the armed-conflicts, become children unaccompanied refugees, and fill many informal shelters and residential centres created in local communities to respond during conflict and crisis.⁷⁸

⁷⁷ UNICEF. (2024). Humanitarian Action for Children in the Middle East and North Africa. Accessed at:

<https://reliefweb.int/report/algeria/humanitarian-action-children-middle-east-and-north-africa-2025>

⁷⁸ Baghdadi, F., Rauktis, M.E., Hands, C., et al. (2024). Using a systems perspective to examine child protection systems and practice: A scoping review. *Child and Youth Services Review*, 157.

<https://www.sciencedirect.com/science/article/pii/S0190740923005789#:~:text=Additionally%2C%20the%20estimated%20500%2C000%20children,rate%20of%20identification%20and%20institutionalisation>

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Evidence on Successful Deinstitutionalisation of Children with Disabilities

Key elements of success

There is a growing evidence base showing the elements of success for sustainable family-focused care systems that meet the needs of all children, including those with disabilities.⁷⁹ Generally, for an inclusive child protection and care system these elements include the components of a functioning system: good laws and policies along with the guidance and tools to implement them; identification of a lead agency and strong coordination mechanisms; data systems and generation of evidence over time; services and systems of service delivery; supportive public attitudes and social norms; a well-planned, developed and resourced social service workforce; and a system of public finance with the resources needed for family support, basic services, and family-based alternative care. These elements are illustrated in the examples that follow.

Examples of well-implemented and sustainable care reform efforts for children with disabilities

Australia: Building evidence

As part of long running care reforms in Australia and informed by the over-representation of children in care with disabilities, there has been considerable investment in strengthening data to publicly track progress on key indicators of system improvements and in research to generate evidence on children's safety and wellbeing when they are in care, such as through the Pathways of Care Longitudinal Study.⁸⁰ In 2020–21, government data on children in out-of-home care showed that disability status was available for 63% of children, with about 30% being reported as having a disability. The most recent data for 2022-23 shows that disability status is now known for 72% of children in care, of whom 21% had a disability.⁸¹ Importantly, there is a clear focus in care reform efforts on ethnic minority groups, who are also over-represented, through the Aboriginal and Torres Strait Islander Child Placement Principle.⁸² Therefore, data is also available specific to these children, including on their disability status showing a higher prevalence rate of children in care amongst this doubly vulnerable group.⁸³ The Pathways of Care Longitudinal Study is the first large-scale prospective longitudinal study of children in care in Australia, collecting data on child, caregivers and placement characteristics, as well as data related to child developmental domains, including physical health, socio-emotional wellbeing and cognitive ability. By following a cohort of children through their placement journey and into adulthood the study is providing insights which have not been available before. Children with

⁷⁹ Maestral International. (2023). Scaling Up Family Care Through Care Reform: A Conceptual Framework. Accessed at: https://maestral.org/wp-content/uploads/2023/05/Scaling-up-conceptual-framework_FINAL.pdf and Hope and Homes for Children. (2022). Families not Institutions: A roadmap for global care reform. Accessed at: <https://www.hopeandhomes.org/news/families-not-institutions/>

⁸⁰ For more information see: <https://dcj.nsw.gov.au/about-us/facsiar/pathways-of-care-longitudinal-study.html>

⁸¹ See publicly available statistics at: <https://www.aihw.gov.au/reports/child-protection/child-protection-australia-2022-23/contents/insights/supporting-children#oohc>

⁸² For more information see: <https://www.aihw.gov.au/reports/child-protection/atsicpp-indicators/contents/indicators/placement>

⁸³ Research Centre for Children and Families, University of Sydney (2022) Children with disability in out-of-home care – summary of the literature.

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disabilities are fully included, the complexity of measurement of disability is being acknowledged and the interaction of disability and care is being explored. A recent publication specific to children with disabilities looked at the well-being of children with and without disabilities and across various care settings. It is reported that children with disabilities tend to have lower levels of wellbeing in care than children without disability, and this is driven mainly by their disability status rather than care factors.⁸⁴

Cambodia: Inclusive policy framework

The Action Plan on Improving Alternative Care for Children, 2023-2027, is an important document outlining service delivery for all types of child victims and vulnerable children in Cambodia.⁸⁵ It has a specific provision that “various efforts shall be made to combat discrimination against certain situations of the children or parents which includes poverty, ethnicity, religion, sex, mental

and physical disability, HIV/AIDS or other severe diseases. According to UNICEF, the deinstitutionalisation of children in Cambodia focuses on transitioning children with disabilities from institutional care to community-based settings, promoting autonomy and integration.⁸⁶ In terms of preventing separation, the national authorities recognise that many girls and boys continue to experience and witness violence, abuse, exploitation and neglect and that their likelihood of being exposed to violence is often exacerbated by negative attitudes and discrimination towards children with disabilities. Some activities within the National Action Plan to Prevent and Respond to Violence Against Children are to develop a particular section of the National Positive Parenting Toolkit for supporting parents of children with disabilities and provide capacity building to implement child friendly, disability inclusive standard operating procedures/protocols for handling cases and reports of violence of children, with particular attention to children with disabilities.⁸⁷

Moldova: Specialised foster care

In Moldova, as part of the country’s National Programme for Child Protection 2022-2026⁸⁸ to achieve a goal of zero children in institutional care, a two-year pilot of specialised foster care for children with complex needs pilot is being implemented. The need for this form of foster care was established through and thorough situational analysis of children’s care in Moldova⁸⁹ which identified various gaps and challenges that needed to be met to end institutional care. The pilot comes under a Collective Impact effort, led by the government and involving several NGOs, and was informed by a desk review of global good practice.⁹⁰

⁸⁴ Cheng, Z. *et al.* (2023). *op cit.*

⁸⁵ Cambodian Ministry of Social Affairs, Veterans and Youth Rehabilitation. (2023). Action Plan on Improving Alternative Care for Children 2023-2027.

⁸⁶ UNICEF. (2024). Inclusion of Children with Disabilities in Cambodia: Identifying priorities for joined actions. Accessed

at:<https://www.unicef.org/cambodia/media/8896/file/Inclusion%20of%20Children%20with%20Disabilities%20in%20Cambodia-Final.pdf.pdf>

⁸⁷ Kingdom of Cambodia, Action Plan to Prevent and Respond to Violence Against Children 2017-2021, Commitment of Steering Committee on Violence Against Women and Violence Against Children.

⁸⁸ See: <https://social.gov.md/en/communication/the-priorities-of-the-national-programme-for-child-protection-for-2022-2026-were-presented-at-an-event-organized-on-international-day-for-protection-of-children/>

⁸⁹ Changing the Way We Care. (2021). Situational Analysis of Care Reform in the Republic of Moldova: Analysis focused on vulnerable groups of children and the prevention of child-family separation.

<https://www.changingthewaywecare.org/wp-content/uploads/2022/07/report-1-care-assessment-ctwwc-md-eng.pdf>

⁹⁰ For more information see: <https://bettercarenetwork.org/library/the-continuum-of-care/foster-care/good-practices-of-foster-care-for-children-with-complex-needs-findings-from-a-rapid-review-of-the>

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The pilot involves a close look at current practice on foster care and adaptation of the recruitment, assessment, training of foster carers with an added emphasis on children with disabilities, to equip them with the skills and knowledge required to care for children with complex needs. Consideration was also given to the benefits and allowances such foster carers would need. Training is followed by matching, placement and provision of appropriate support and monitoring to foster families. In addition, the pilot includes additional training for service providers, including medical care professionals, to ensure they are also equipped to support the children and families. The pilot includes a strong monitoring and learning framework in order to provide the evidence needed for further adaptation and scale up across the country.

Rwanda: Training for the local workforce and building community awareness

In Rwanda, as part of the government's ambitious *Tubarerere Mu Muryango* (Let's Raise Children in Families) programme,⁹¹ emphasis was placed on building an effective workforce to ensure children and families vulnerable to separation or reintegrating from residential care were properly assessed and supported. Following the first phase of the programme which did not have a specific focus on children with disabilities, the evaluation reported that placement of children with disabilities into families utilizing the existing model was challenging. Therefore, during the second phase the training approach was adapted to make it more inclusive which was considered more appropriate than development of a stand-alone or parallel system which can contribute to further stigmatization and discrimination. This included setting out clear roles and responsibilities for volunteers and professionals, providing oversight and referral systems. Alongside pre-service and in-service training for professional social service workers, a dedicated training approach was designed for the *Inshuti z'Umuryango* (Friends of the Family), the volunteer community-based cadre of the workforce. The aim of the training was to raise awareness on "the rights and needs of children with disabilities, so that they can be allies in helping children with disabilities and families to live in their communities free from stigma and discrimination."⁹² The training includes: the importance of including children with a disability, definitions of disability, and overview of the types and effects of disability, issues related to stigma and discrimination; and consideration of why the words used to talk about disability are important. The training also covers the use of a parenting approach for caregivers of children with disabilities and wider community members.

Kenya: National Care Reform Strategy and examples of working with OPD⁹³

Kenya's National Care Reform Strategy for Children (2022) makes explicit the need to prioritise children with disabilities in all care reform processes. For example, in terms of the prevention of separation and family strengthening, it delineates the importance of campaigns to tackle false information about and stigma against children with disabilities; registration of children with disabilities to ensure targeted services can be appropriately planned and

⁹¹ For more information see: <https://www.unicef.org/rwanda/reports/child-care-reform-programme-rwanda>

⁹² National Child Development Agency (Rwanda) and UNICEF (2021) Package for The Tubarerere Mu Muryango programme ('Let's raise children in families'): Supporting children with disabilities & their families: Training module for Inshuti z'Umuryango (Friends of the Family). <https://bettercarenetwork.org/library/principles-of-good-care-practices/leaving-alternative-care-and-reintegration/training-package-for-the-tubarerere-mu-muryango-programme-%E2%80%98let%E2%80%99s-raise-children-in-families%E2%80%99>

⁹³ UNICEF and Changing the Way We Care. (2021). *op cit*; CTWWC. (2023). Insight: Disability inclusion in Kenya's Care Reform. Accessed at: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/insight-disability-inclusion-in-kenyas-care-reform>

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directed; services for children with disabilities and their caregivers, including respite care, inclusive day care services, peer support groups, enhanced cash transfers, and specialist community-based rehabilitation and health services; and capacity building of social workers in relation to disability.⁹⁴ When it comes to practical progress, the disability reflection forums initiated by Changing the Way We Care, a global care reform initiative, provided a platform for participants to learn and understand care reform from the perspective of disability inclusion. Government agencies, larger non-governmental partners, and representatives from OPDs and civil society organizations used these forums to meet periodically and take stock of the disability inclusion journey within Kenya's care reform. Some of the reflections included: how community leadership and child protection committees have enhanced their support mechanisms and embraced disability inclusive case management and other tools. One county example, showed that set aside funds were available to support education scholarship, access to assistive devices, financial support for caregivers with disabilities, and support for disability networks. Other counties are piloting government structures which support children with disabilities and access to registration for special cash transfers.

Uganda: Changing social norms

Ekisa Ministries, a faith-based organisation in Uganda, has found that the biggest barrier to transitioning children with disabilities from residential to foster care is the belief that these children cannot be cared for in families. This view is held by many social workers, care home staff, and prospective foster carers, and is closely linked to high levels of ignorance and discrimination around disability. Ekisa argues that although the focus of policies and programmes for children with disabilities is often on providing for children's physical needs, it is cultural attitudes that most require change. To overcome this barrier, Ekisa staff take stakeholders through a journey which begins with reducing ignorance around disability, before moving on to enhancing empathy and encouraging relationship-building with and support to those with disabilities in the community. Eventually, community members are encouraged to think about whether they might provide care for a child with disability. Giving prospective foster carers a chance to ask questions, discuss their fears and hear from others who have successfully fostered children with disabilities has also been of great value.

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EU: Regional body policy and funding as driving reform

The European Union has been supporting deinstitutionalisation and care reform for many years through legislation, guidance and funding. In 2021, the European Commission adopted the Strategy for the rights of persons with disabilities 2021-2030,⁹⁶ the second strategy of its kind, to drive improvement in the lives of children and adults with disabilities. The 2012 Common European Guidelines on the Transition from Institutional to Community-based Care⁹⁷ provides practical guidance for policy makers on making a sustained transition from institutional care to family-based and community-based alternatives. These guidelines

⁹⁴ Government of Kenya. (2022). National Care Reform Strategy for Children in Kenya (2022-2032). Accessed at: <https://bettercarenetwork.org/national-care-reform-strategy-for-children-in-kenya-2022-2032>

⁹⁵ UNICEF and Changing the Way We Care. (2021). *op cit*.

⁹⁶ European Commission (2021). Union of equality: Strategy for the rights of persons with disabilities 2021-2030. <https://op.europa.eu/en/publication-detail/-/publication/3e1e2228-7c97-11eb-9ac9-01aa75ed71a1/language-en>

⁹⁷ European Expert Group on the Transition from Institutional to Community-based Care (2012). Common European Guidelines on the Transition from Institutional to Community-based Care. <https://deinstitutionalisation.com/wp-content/uploads/2017/07/guidelines-final-english.pdf>

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are designed to be used alongside the Toolkit on the use of European Union Funds⁹⁸ for the same purpose. The combined approach to providing policy, guidance and funding has ensured that care reform remains on the agenda of member states and those seeking to join the EU.

Guatemala: Adoption and family care for children with disabilities

Guatemala suspended intercountry adoptions in 2007 and established a strong domestic adoption system. In 2010-2011, the *Consejo Nacional de Adopciones* (CNA) identified a group of adoptable children with low placement prospects who risked growing up in institutions. To address this, the "Creeré" ("I will believe") programme was launched to promote the adoption of children with disabilities and other special needs.⁹⁹ The CNA implemented a "priority adoption" programme with creative communication strategies, including regional campaigns and media involvement. Additional initiatives, such as the "*Ponte en su lugar*" ("Put yourself in his/her place") campaign, aimed to reduce stigma and raise awareness around disability.¹⁰⁰ Improvements were made to the system of preparing adoptive families. These measures increased interest in priority adoptions and aided in deinstitutionalisation efforts for children with disabilities.

Strength of evidence and identification of gaps

As the extensive references to documentation in this review shows, there is a growing body of literature and evidence on the situation of children with disabilities in alternative care and the efforts being made to promote a disability inclusive approach to care reform around the world. It is encouraging to find examples of promising practices from every region and across the components of the care system: from policy, financing and data collection to the workforce, service delivery and social norms. The literature includes robust research studies, deeper dives into specific case studies, policy and practice guidelines, and learning and advocacy pieces. Within this there is an increasing number that involve children and young people with disabilities directly, contributing their perspectives and as co-designers. However, there remains a long way to go. The literature reviewed also highlights several gaps:

- > Much of the more robust data collection and research studies come from North America and Europe, there is a great need to invest in studies in other regions to further explore the similarities and differences that are being experienced by children with disabilities in care and families needing support to prevent separation. There then needs to be systematic literature reviews and evidence syntheses to bring together the learning from across these diverse experiences.
- > Research and practice guidance need to consistently take a disability inclusive approach. Children with disabilities must be included within research, especially longitudinal studies that are able to explore differences for these children over time as their care and disabilities change.¹⁰¹

⁹⁸ European Expert Group on the Transition from Institutional to Community-based Care (2014). Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care, Rev. Ed. <https://deinstitutionalisation.com/wp-content/uploads/2017/07/toolkit-10-22-2014-update-web.pdf>

⁹⁹ Santos Contreras de Uclés, S.A. Adopciones prioritarias en Guatemala. CNA. At: RELAF. Seminario 2016. Ciudad de Panamá, Panamá | 12, 13 y 14 de Octubre de 2016. Available at: <https://relaf.org/seminarios/?id=315>.

¹⁰⁰ CNA (2019). Línea Directiva para promover adopciones prioritarias de niñas, niños y adolescentes. Available at: https://www.cna.gob.gt/Documentos/InformacionPublica/N6/Linea_Directiva_Adopciones_Prioritarias.pdf.

¹⁰¹ Cheng, Z. *et al.* (2023). *op cit.*

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- > Whilst there are some positive examples, much of the literature on children with disabilities is missing the views and engagement of children in care and care leavers themselves.¹⁰²
- > Finally, there needs to be continued efforts, such as those being led by UNICEF, towards progressing agreement on definitions and linked measurement approaches for alternative care options and disability, so that these can be brought together to allow consistent data collection for children with disability in alternative care.

¹⁰² Baker, C. & Briheim-Crookall, L. (2024). *op cit*.

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Key Resources

CRPD Guidelines on Deinstitutionalisation Including in Emergencies were developed by the Committee on the Rights of Persons with Disabilities (CRPD) with input from over 500 individuals with disabilities. They aim to guide and support States in planning and executing deinstitutionalisation processes and preventing institutionalisation.

<https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalization-including>

The Disability Inclusion in Care Reform Toolkit is a collection of work developed from the experience of many practitioners and organisations. It was collated by Changing the Way We Care. <https://bettercarenetwork.org/toolkit-for-disability-inclusion-in-care-reform>

Scaling Up Family Care through Care Reform is a conceptual framework for scaling approaches towards family-centred care systems for all children. It includes building a national vision for the care system, identifying interventions ready for scaling, coordination and monitoring. https://maestral.org/wp-content/uploads/2023/05/Scaling-up-conceptual-framework_FINAL.pdf

Family Care for Children with Disabilities: Practical Guidance for Frontline Workers is a resource for people working with children and families around family strengthening and family-based alternative care. <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/family-care-for-children-with-disabilities-practical-guidance-for-frontline-workers-in-low-and>

Families Not Institutions is a guidance roadmap developed by Hope and Homes for Children with input from many other organisations. It draws on the experience in multiple contexts to discuss how to create the conditions for care reform. It then provides a set of recommendations for how to implement change, and provides examples of care reform around the world. <https://www.hopeandhomes.org/publications/families-not-institutions/>

Enabling reform: Why supporting children with disabilities must be at the heart of successful care reform is a compelling position paper written by the Better Care Network and Family for Every Child. <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/enabling-reform-why-supporting-children-with-disabilities-must-be-at-the-heart-of-successful-child>

EU Funds Checklist to Promote Independent Living and Deinstitutionalisation supports helps to ensure EU funds are contributing to independent living and inclusion in the community, including development of quality family-based and community-based services, prevention of separation of children with disabilities from their families, and prevention of institutionalisation of children. <https://deinstitutionalisation.com/wp-content/uploads/2021/07/updated-checklist-new-eeg-logo.pdf>

Save the Children: Guidelines to Child Care Reform Implementation These guidelines are intended for technical staff working in child protection, specifically, those focusing on family strengthening, alternative care of children, and child rights governance, in middle-income countries. The guidelines have been developed based on Save the Children's research and experience in the Eastern Europe sub-region.

<https://resourcecentre.savethechildren.net/document/guidelines-child-care-reform-implementation/>

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Helpdesk services are provided by a consortium of leading organisations and individual experts on disability, including Social Development Direct, Sightsavers, ADD International, Light for the World, Humanity & Inclusion, BRAC, BBC Media Action, Sense and the Institute of Development Studies (IDS). Expert advice may be sought from this Group, as well as from the wider academic and practitioner community, and those able to provide input within the short time-frame are acknowledged. Any views or opinions expressed do not necessarily reflect those of FCDO, the Disability Inclusion Helpdesk or any of the contributing organisations/experts.

For any further request or enquiry, contact enquiries@disabilityinclusion.org.uk

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