

Changing THE WAY WE care™

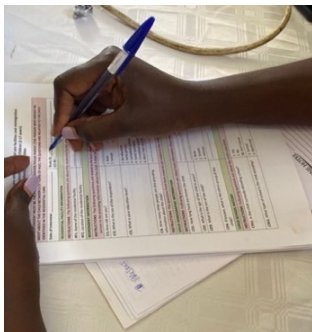
Learning Brief: Disability inclusion in care reform

Introduction

According to the UN Convention on the Rights of Persons with Disabilities, persons with disabilities 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.¹ Many rights of persons with disabilities around the world are violated, including the right to be raised in a family environment. Globally, children with disabilities are disproportionately represented in residential care facilities, with many spending years there only to leave as adults.² *Changing the Way We Care*SM (CTWWC) is a global initiative dedicated to finding solutions so that all children can grow up in family homes rather than residential care, no matter where the child lives or what their challenges may be. Due to the high burden of children with disabilities living outside family care, CTWWC has committed to using disability inclusive approaches to care reform so that children with disabilities are no longer left behind. In this context, disability inclusion means ensuring care reform policies, practices and systems consider the needs of children with disabilities and their caregivers. At the community level, it includes creating enabling environments with less stigma and more coordinated service provision. At the family level, it involves giving caregivers the tailored, holistic support they need to care for their children with love and confidence.

Inclusion is the process of taking necessary steps to ensure that every person is given an equal opportunity to develop socially, learn and enjoy community life.

Although reunification and reintegration of children and youth with disabilities is complex, it is within reach with the right stakeholder engagement, planning and persistence. These new insights come from experiences in Moldova, Haiti, and Kenya and sharing from members of the Transforming Children's Care Global Collaborative Platform Disability Inclusion in Care Reform Community of Practice. Frontline workers who are reunifying children with disabilities note it is important to be diligent in finding the right resources tailored to the unique needs of each child. Specifically, take a measured approach that allows time to understand the needs of the child and their caregiver(s), extended family and community. Educating caregivers and service providers about the child's rights is also effective in helping children access the holistic support they need. Most importantly, start the process early and count on it taking more time (and money) to complete than for a child without a disability.



The following will outline what CTWWC has learned by adopting disability-inclusive approaches.

What the numbers tell us

Evidence and practice suggest disproportionate representation of children with disabilities in residential care facilities. Many of these children are spending more time in care than their peers and are leaving as adults – or at times are remaining in care *through* adulthood. Yet, the data is inconsistent. CTWWC has made an effort to understand the prevalence of developmental delays, disability and functional

¹ <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

² Goldman, Philip S., et al. "Institutionalisation and deinstitutionalisation of children 2: policy and practice recommendations for global, national, and local actors." *The Lancet Child & Adolescent Health* 4.8 (2020): 606-633.



Data from 2020 situational analysis in Kenya

challenges in working with children and families. For example, the [Five County Situation Analysis](#) conducted with the government in Kenya in 2020 looked at over 8,000 children in 210 residential care facilities and found that anywhere from 1% to 8% of children in any given facility had an identified disability.

One exciting piece of research, taken up over the last couple of years in collaboration with Johns Hopkins University, looks at how the [UNICEF/Washington Group Child Functioning Module \(CFM\)](#) can be used to identify the needs of children in Kenya's charitable children's institutions, increase staff understanding of disability and improve inclusive case

management practices. This research found a higher prevalence of disability when child functioning was the measurement. Initial qualitative findings from the CFM Study suggest that: staff in CCIs have varied experiences working with children with disabilities; lack of disability awareness leads to stigmatization within and beyond residential care facilities; and providers of care would benefit from more comprehensive education and training around disability.

The data from the CFM tool would enable data driven decisions in case management

- CFM data can help make a better case plan for all children
- As part of case management process, the CFM tool would help with early identification of children with disabilities to better understand their needs and possible interventions
- Empowering for house parents
- CFM data would enable better planning as the child transitions from the institution to family-based care

The study found approximately 10% of children in the CCIs taking part in the research were found to have functional limitations.

Working with others

Meeting the holistic needs of children with disabilities requires collaboration from many different stakeholders across government, civil society and service providers. In [Guatemala](#), [Kenya](#), and [Moldova](#), CTWWC has worked with government offices for education, disability, protection, health and social welfare services. Like any child, children with disabilities need access to a variety of services to thrive, yet providers often don't have the specialized skills or awareness to tailor services to meet these children's needs. Organizations of persons with disabilities (OPDs) and parents of persons with disabilities have provided valuable input on how to tailor activities to better meet the needs of children with disabilities and their families. CTWWC has also engaged OPDs and other civil society groups to bolster government capacity to fill service through training and improved service coordination.

CTWWC staff have learned that working with government lets you go farther, faster!

During reflection meetings with disability networks supported by CTWWC Kenya, network members and CTWWC staff said they were able to empower government, at both local and national levels, to take a leadership role in meeting the needs of children with disabilities and their families. With government counterparts, the networks mapped disability service providers across their respective counties, and then established and trained disability assessment teams to conduct assessment and registration outreach activities. The disability networks, which improve coordination and coverage of disability services across the county, also learned that having supportive policies in place helped advance their work. Once county-level government adopted a new disability policy, it became easier to expand access to services that help children with disabilities live in family care.

In CTWWC countries, service mapping is common. While there is a tendency to want to overcomplicate the process, it is best to make mapping simple. Avoid complicated tools - rather, note who provides what services and

Innovating with Technology

One disability network created a WhatsApp group where members share information, coordinate activities and make referrals. This has improved communication, collaboration and mobilization across members. Now, with increased alignment to serve all children with disabilities without duplication - and do so through a multisectoral approach - the network is able to holistically address service gaps within the county.

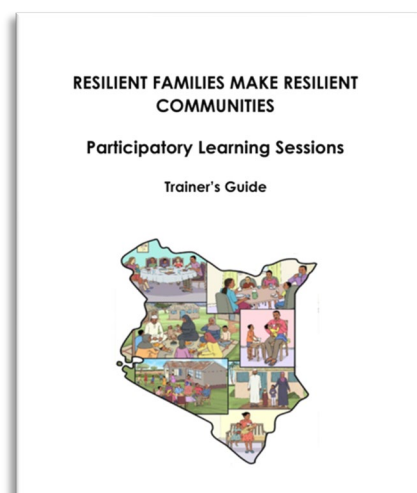
in what location, and then take down their contact information. Incorporate information about who provides rehabilitation and assistive devices, something overlooked in many mapping exercises. These devices are a key service to build parents' capacity to care for their child at home and help children's physical, social/emotional development. Be sure to conduct mapping early within a project's timeline and revise information periodically. Finally, ensure dissemination of service mapping (an important step that is often skipped) and ensure partner staff and frontline workers have access to the service maps so that the information can be put to good use.

In Kenya, CTWWC partners who are reintegrating children with disabilities into family care have said that mapping disability-related services is especially important.

Addressing stigma

As CTWWC has seen in Haiti, Kenya, and Moldova, stigma can make it hard for caregivers to keep children in their families. Even when service coverage is expanded, stigma can keep some caregivers and their children with disabilities from seeking services. CTWWC has learned that stigma must be addressed within the family, communities and residential care facilities, service providers and caregivers. The 2022 study published in *Global Studies of Childhood*, [*The Critical Intersection between Child Reintegration and Community Connectedness*](#), shares CTWWC Guatemala's learning around the criticality of addressing stigma in reintegration and how increasing community connectedness is important for successful reintegration, especially for families of children with disabilities.

The *Resilient Families Make Resilient Communities* approach in Kenya is based on social-behavioral change strategies, or culturally and contextually appropriate ways to encourage changes in behaviors through access to information and services. CTWWC is employing the messages and discussions from this with communities and families to strengthen families and mitigate or reduce the risk of family separation, which includes addressing stigma around childhood disability. The goal is to empower caregivers through the promotion of behaviors and norms that address barriers, leading to changes in attitudes and adoption of positive behaviors towards family-based care for children.



To overcome stigma, it's helpful to use multiple approaches that target this range of stakeholders. Neither empowering the household nor messaging in the community is enough on its own!

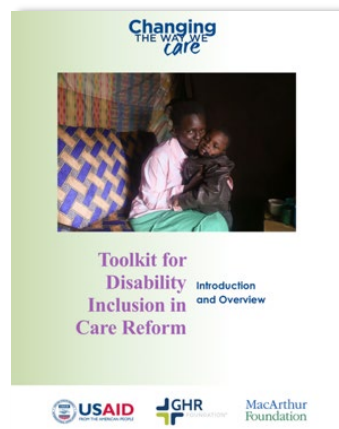
Building capacity for inclusion

Capacity building is foundational to disability-inclusive care reform. As CTWWC staff and partners have committed to better serve the needs of children with disabilities, it has become clear that ample attention should be given to

trainings, training topics and the frequency of trainings. Across CTWWC countries, disability awareness and inclusion training for CTWWC staff and partners has hastened progress. A good starting point to build capacity among CTWWC staff, partners, frontline workers and parents of children with disabilities is beginning with basic training topics, including disability etiquette and how to plan for/respond to accommodation requests. For frontline workers, select topics that boost skills needed to work directly with children with disabilities. For example, social workers and other residential care staff requested training on disability-inclusive case management, referral mechanisms and minimum standards of care for children with disabilities. To improve engagement during the trainings, CTWWC asked participants to help select training topics. OPDs were also brought in as co-facilitators to ensure training content was respectful and reflected needs and realities of children with disabilities and their families. When it came to building parents' confidence and skills, CTWWC asked them what information they needed to care for their children with disabilities, and then designed content to address those specific requests. One emerging theme was that parents seldom knew about disability rights, which is important information they need to advocate for their children. Many were also unaware of child development, so CTWWC integrated that content into parenting manuals.

Train everyone on the team. Don't leave disability inclusion to one person to champion alone. Ensure staff know etiquette and how to plan for/respond to accommodation requests. Begin with the basics!

The **Toolkit for Disability Inclusion in Care Reform** was published in FY22 and represents a collection of work developed from the experience of many practitioners and organizations. Its aim is to increase the capacity and confidence of those working in children's care, child protection and family strengthening to mainstream disability through every step, utilizing improvements to systems, practices, skills and attitudes.



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