



# INSIGHT

## Disability Inclusion in Kenya's Care Reform

Changing the way We Care (CTWWC) is an initiative designed to promote safe and nurturing family care for children either reunifying from institutions or those at risk of child-family separation. This includes strengthening families to provide for their children as well as reforming national systems of care for children including family reunification and reintegration and development of alternative family-based care.

### INTRODUCTION & BACKGROUND

**Disability inclusion** means understanding the relationship between the way people function and how they participate in society, and making sure everybody has the same opportunities to participate in every aspect of life to the best of their abilities and desires. Creating a society where children with disabilities have equal access and opportunities in all spheres of life means an inclusive society where children with disabilities are treated with respect and have their rights recognized. It means all children fully participate in education, social activities and

community, access to health, identification and registration and can live in families.

**Disability inclusion** means breaking down barriers to promote a society that values diversity and accessibility for everyone.

In 2023, CTWWC Kenya included a disability inclusion reflection learning exercise aimed at collecting views and feedback, and documenting how the initiative had impacted on lives of caregivers and children with disabilities, and how disability issues were included in the care reform agenda.

In 2023, the WHO estimates that over one billion people, or 16% of the world's population, have a disability. 80% live in developing countries.

Some women, men and children with disabilities are fully integrated in society and are participating in and actively contributing to all areas of life. However, many still face discrimination, exclusion, isolation and



even abuse. Many persons with disabilities live in extreme poverty, in institutions, without education or employment opportunities and face a range of other marginalizing factors. Today, persons with disabilities are all too often denied the right to make decisions for themselves. The discrimination they face is widespread, and even trickling in to services and programs aimed at preventing child-family separation and ensuring reintegration of children with disabilities into their families or other alternative family care.

According to UNICEF, There are 240 million children living with disabilities in the world. Half of them are out of school. Many are invisible, hidden by their families and left behind by government programs.

**Children with disabilities** are one of the most excluded and marginalized groups in the world, and often face multiple challenges in realizing their human rights, including to live in family and community. Disability inclusion is guided by the United Nations Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

CTWWC has found that disability is one of the drivers of child-family separation and child placement in residential care. Children with disabilities are often the last to leave the facility and stigma and lack of services lead families to believe they cannot adequately care for them.

CTWWC has worked to live by the ideals of disability inclusion, believing and putting to practice that all children, regardless of abilities, have the right to reach their full potential. The initiative seeks to raise awareness on family care with families, children and communities, in addition to demonstrating change in four counties in Kenya and with the national government. For inclusivity, CTWWC works with all people in the community to ensure that they get the required services to avoid child-family separation as a result of disability.

## THE LEARNING EXERCISE

The disability reflection forums provided a platform for participants to learn and understand care reform from the perspective of disability inclusion. They allowed CTWWC and partners such as the Directorate of Children's Services (DCS), Ministry of Health (MOH), Directorate of Social Development (DSD), Ministry of Education, organizations of persons with disabilities and other civil society organizations to take stock of the disability inclusion journey within Kenya's care reform.

### Objectives of the disability exercise

- To understand the views of government and non-government actors around the barriers and enablers of reintegrating children with disabilities into families and communities;
- To gather the most-significant-change themes from the perspective of various project participants;
- To articulate and agree on key lessons to share more widely;
- To understand and document project participant's experiences around reintegration of children with disabilities; and
- To allow project participants to explore challenges and catalysts of success for family reintegration of children with disabilities.

### The learning reflection questions

What are the barriers and facilitators for prevention and reintegration of children with disabilities?

What is the current support system for children with disabilities for reintegration and prevention of family separation?

The approaches used during the three county disability learning activities were aimed at responding to the disability learning objectives and included: small group discussions, gallery walks, brainstorming sessions, plenary discussions and presentations.

## CONCLUSIONS FROM REFLECTION SESSIONS

The CTWWC initiative includes children with disabilities in all facets of the programming. While realizing that nearly everyone faces hardships and difficulties at one time or another, CTWWC sees that **children with disabilities encounter barriers more frequently and that those barriers have a greater impact as they are often multiple and complex.**

**Barriers** are the factors in a person's environment that, through their absence or presence, limit functioning and create disability. They include attitudinal, communication, environmental barriers and institutional barriers.

**Enablers** are the resources, tools, services, attitudes and supports available to allow people with disabilities to perform their daily tasks.

**Attitudinal barriers** were the most mentioned during the reflection learning activity, across counties. They were described as contributing directly to other barriers. For example, access to services and different agencies, and even schools, limits a child with a disability from participating in everyday life and common daily activities, while attitudes perpetuate ideas such as "children with disabilities do not want to be with other children". Attitudinal barriers includes stereotyping, stigma, prejudice and discrimination. These harmful attitudes cause labelling and grouping, rather than viewing each child as individual. Some examples of stereotypes included:

- Children with disabilities have a poor quality of life or are unhealthy because of their impairments.
- Children with disability are a personal tragedy to the family.
- Children's disabilities need to be cured or prevented – and they might be contagious.
- Children's disabilities are a punishment for wrongdoing.

- Children with disabilities lack ability to behave as expected in society.

**Communication Barriers** are experienced by people who have disabilities that affect hearing, speaking, reading, writing, and or understanding, and who use different ways to communicate than people who do not have these disabilities. Examples of communication barriers include:

- Written child awareness promotion messages with barriers that prevent people with vision impairments from receiving the message. These include:
  - Use of small print or no large-print versions of material, and No Braille or versions.
  - Auditory health messages may be inaccessible to people with hearing impairments, including: that Oral communications without accompanying with Kenya Sign Language.
  - The use of technical language, long sentences, and words with many syllables may be significant barriers to understanding for people with cognitive impairments.

**Environmental Barriers** are structural obstacles in natural or man-made environments that prevent or block mobility (moving around in the environment) or access. Examples of environmental barriers can include steps and curbs that block a child with mobility impairment from entering a building or using a sidewalk; play items and equipment that requires a child with mobility impairment to stand; and/or the lack of relevant assistive technology (assistive, adaptive, and rehabilitative devices).

**Institutional barriers** are frequently related to a complete lack of or enforcement of existing laws and regulations that require programs and activities to meet the needs or address all children. Examples of policy barriers can include lack of provisions for qualifying individuals for benefit from government programs, services, or other benefits, but also more indirect barriers such as in adequate public financing and lack of accurate and disability desegregated data.

## SUMMARY OF BARRIERS AND ENABLERS

BARRIER TYPE	BARRIERS	ENABLERS
<b>Attitudinal</b>	<ul style="list-style-type: none"> <li>• Ignorance</li> <li>• Stereotypes</li> <li>• Prejudice</li> <li>• Fear of the unknown</li> <li>• Lack of empathy</li> <li>• Lack of knowledge on disability</li> <li>• Lack of parenting skills</li> </ul>	<ul style="list-style-type: none"> <li>• Creating awareness through visibility</li> <li>• Radio spots</li> <li>• Fun community events</li> <li>• Training and capacity building</li> <li>• Peer support groups</li> <li>• Children’s play groups</li> <li>• Formal advocacy campaigns</li> <li>• Positive parenting classes</li> </ul>
<b>Communication</b>	<ul style="list-style-type: none"> <li>• Language / speech</li> <li>• Technology gaps or lack of access to technology</li> <li>• Lack of alternative modes / interpretation</li> <li>• Lack of plain, non-jargon, language</li> <li>• Print size and fonts</li> <li>• Cross cultural communication</li> </ul>	<ul style="list-style-type: none"> <li>• Use of clear and simple language</li> <li>• Use of non-jargon vocabulary</li> <li>• Use of pictograms and other visuals</li> <li>• Assistive technology</li> <li>• Translation and interpreters</li> <li>• Braille and large print</li> </ul>
<b>Environmental</b>	<ul style="list-style-type: none"> <li>• Noise</li> <li>• Transportation barriers – access, distance, cost</li> <li>• Lack of accessibility features (ramps, elevators)</li> <li>• Inaccessible roads and pathways</li> <li>• Lack of assistive devices</li> </ul>	<ul style="list-style-type: none"> <li>• Adjusting accessibility features</li> <li>• Accessibility audits</li> <li>• Accessible infrastructure improvements (to roads, houses, service and other buildings)</li> <li>• Provision of assistive devices</li> </ul>
<b>Institutional</b>	<ul style="list-style-type: none"> <li>• Inadequate basic services (health care, education, shelter/housing)</li> <li>• Lack of health insurance or access to</li> <li>• Limited public resource put to basic and specialized services</li> <li>• Lack of reasonable accommodation in employment</li> <li>• Lack of legal frameworks and policies</li> <li>• Lack of data to support change and documentation on what works</li> <li>• Case management procedures that are not inclusive</li> <li>• Lack of services and programs</li> </ul>	<ul style="list-style-type: none"> <li>• Disability inclusive specific policies</li> <li>• Disability disaggregated data</li> <li>• Inclusive budgeting</li> <li>• Trained human resources (e.g. teachers trained in inclusive education)</li> <li>• Support for reasonable accommodation</li> <li>• Disability and child-friendly legal frameworks and policies</li> <li>• Child-centered budgeting</li> <li>• Support development of inclusive services and legal framework</li> <li>• Engagement of organizations of persons with disabilities</li> <li>• Diversity of services and programs</li> </ul>

### ABOUT INCLUSIVE SYSTEMS

Systemic failures to provide an adequate support system for children with disabilities as related to both reintegration and prevention of family separation was an evidence issue coming out in the reflection exercise. Kenya is signatory to the UNCRPD

and its Article 23(4), which unequivocally states that *children should not be separated from their parents or caregivers because of their disability or that of their parent/caregiver.*

The appropriate systemic response is compounded by lack of data regarding how parents and caregivers with risks can and do access services. The data that are

available suggest that caregivers with disabilities themselves are over-represented, nationally, and internationally, in the child welfare system. CTWWC's data found that caregivers of children with disability are more likely to experience removal of children from their care. **The apparent gap between the prevalence of disability and low participation in support services for children to prevent family separation raises concerns about the effectiveness of those very services in understanding and addressing needs.**

The discrimination faced by caregivers with their own disabilities is reflected in, and reinforced structurally by, the scarcity of inclusive, accessible basic and specialized support services. **For many caregivers with disabilities, the possibility of family preservation, or, in cases where children are already separated, family reunification is overshadowed by the lack of appropriate and accessible services.** Poverty and related issues such as inadequate or insecure housing, lack of registration, and lack of access to social services are identified as significant complicating factors driving children with disabilities into care. At the same time, the social service workforce often lacks the capacity or specialist knowledge to either identify

or address the specific and diverse needs and realities of children with disabilities and their caregivers.

CTWWC finds that many families living with disability, of the caregiver or the child, live in conditions of compounded disadvantage, including financial vulnerability and substandard living conditions, housing insecurity and social isolation.

The reflection activity led to a conclusion by participants that **the greatest need is for a system of comprehensive services that are accessible, responsive, flexible, and tailored to the needs of families, including families experiencing disability; one that supports families to stay together and is consistent across the counties of Kenya.** The current support system of Kilifi County seems well anchored in the policy framework. The county has also set aside funds to support education scholarship, access to assistive devices, financial support for caregivers with disabilities, support for disability networks.



Photo by Angela Muathe / CRS

The community leadership and child protection committees also have enhanced their support mechanisms and embraced disability inclusive case management and other tools. Other counties are piloting government structures which support children with disabilities and access to registration for special cash transfers.



Photo by Philip Laubner / CRS

### FACTORS LEADING TO MORE INCLUSIVE SYSTEMS

- Government and service providers adopt an inclusive case management approach.
- The social service workforce and allied workers have capacity built specific around disability inclusion.
- Government structures have awareness of the data on children with disabilities and the services needed / service gaps.
- Specially targeted services exist, such as
  - NHIF targeting children with disabilities and their caregivers.
  - Targeted enrolment of persons with disabilities, into UHC (universal health care).
  - Cash transfers under social protection provided by NCPWD.
  - Education scholarship, bursary, and education assistive technology.
  - Legal assistance.
  - Accessible housing.
- Existence of disability-focused NGOs and specialized disability services by non-governmental organisations.
- Existences of support groups and community-based interventions for caregivers on parenting, child care, and economic empowerment
- Functional mechanisms for referral for disability assessments.
- Accessible disability registration with NCPWD.
- Systems for inclusive school placement.
- Provision of assistive devices both through government bursaries and non-government providers.
- County government budget allocation of assistive devices.
- Collaboration between government structures for awareness raising and those for service provision.
- Existence of functioning organizations of persons with disabilities (OPDs) and disability champions.
- Existence of low or no cost parenting skills programs
- Adherence to national legislative frameworks and policies: Children’s Act 2022, Disability Act 2003, UNCRC and UNCRPD, the Constitution 2010, welfare program Inua Jamii, Alternative Family Care Guidelines 2014.
- Existence of county-specific strategies and acts such as County Child Protection Strategies and County Disability Acts.
- Presence of inclusive schools, vocational training and other educational programs.
- Visible disability awareness and stigma reduction campaigns.

## PRIMARY RECOMMENDATIONS

- In order to be inclusive, family strengthening approaches aimed at preventing separation should provide for a range of needs and strengths of each family, and include peer support and community connections to help reduce isolation and address stigma while providing caregivers a network of supportive relationships.
- Ableism in support systems and service provision starts with the widespread failure to be inclusive in case management. From identification to case closure, this contributes to inappropriate and unresponsive case work based on individual family and child. Case management packages must be disability inclusive and designed to address all the kinds of barriers, including communication and attitudinal.
- Data should be collected with respect to the demographics of children with disabilities in order to inform planning, resource allocation and provision of services, and enhance accountability for outcomes that are disability-sensitive.
- Limited capacity of social service workers around disability should be consistently addressed through training, mentoring and supervision. This includes training on understanding disability and communicating and working effectively with people with disabilities and how to understand biases and
- Data should be collected on children and caregivers who access different support systems and services and aggregated for disability in order to plan for, promote, and resource local services.
- Organizations representative of the disability community and children's advocacy organizations should be supported to be active in the care reform sector, policy discussions, public review processes, etc.
- Disability learning reflections provide an opportunity to check against milestones and progress around disability inclusion. By doing these across government and non-government partners more awareness and buy-in is built for further improving services and systems. Reflection becomes one of the major catalysts of change.

**Need to know more?** Contact *Changing the Way We Care* at, [info@ctwwc.org](mailto:info@ctwwc.org) or visit [changingthewaywecare.org](http://changingthewaywecare.org)

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