CHILDREN WITH DISABILITIES AND CARE REFORM IN EASTERN AND SOUTHERN AFRICA
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Introduction

Care reform is underway across the Eastern and Southern Africa region to try to reduce reliance on harmful institutional care and ensure children can grow up in safe and nurturing families. In several countries, significant progress has been made with improvements to policies, guidance and workforce capacity, and many children have been reintegrated into families. However, discussions with governments, UNICEF country offices and other care reform actors suggest that not all groups of children have benefitted equally from reforms. Although there are examples of good practice in the region, policy makers and practitioners report struggling to ensure the better care of children with disabilities. This paper seeks to highlight the importance of placing support for children with disabilities and their families at the center of care reform efforts, and provides examples from across the region of how this can be done.

Understandings and definitions of disability vary by context. This paper uses a social model of disability that defines persons with disabilities as 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. This way of understanding disability encourages policy makers and service providers to challenge the discrimination and social exclusion that leads to difficulty accessing services and can lead to separation. It motivates efforts aimed at the full integration of children with disabilities into families and communities. This work requires both behaviour change and changes to policies, services and support.
Children with disabilities in Eastern and Southern Africa

The most recent estimates indicate that there are between 93 and 150 million children with disabilities under the age of 14 worldwide. In Africa, up to 5.1 per cent of children in this age group are said to have moderate or severe disabilities, including a range of challenges in one or more of the following areas: cognition, communication, mobility/gross motor skills, fine motor skills, self-help skills, social and emotional skills, and hearing, visual and other impairments. Although boys and girls with disabilities are an understudied population, it is well established that they experience generally poorer health and lower levels of education than those children without disabilities, and are at greater risk of poverty, violence, social exclusion and family separation. To a large extent, these outcomes are attributable more to discrimination by policy makers and policies, frontline workers, families and communities than they are to disability per se. Marginalisation, lack of services, and non-existent or insufficiently enforced legal protections are particularly common for children with disabilities in resource-constrained settings, including many contexts in Eastern and Southern Africa. Despite the numerous economic, social, cultural and physical barriers that they face in their everyday lives, there is a dearth of services available to people with disabilities and their families across the region.

Why should work with children with disabilities be a central part of care reform?

There are four main reasons why children with disabilities should be placed at the heart of care reform agendas.

1. Families that care for children with disabilities at home receive little or no support. Health, rehabilitation, education, and recreation services for children with disabilities are non-existent or under-resourced in many settings in the region. Parents or other family caregivers are often unable to balance work and care provision and receive little support in the form of child care or poverty alleviation programmes. In some contexts, children with disabilities are considered to be a burden or a curse and misconstrued assumptions about their intelligence and capacities mean that many are stigmatised and socially excluded. The result is that even informal support from extended families or community members is often not provided to those caring for children with disabilities. Parents or other caregivers often have to struggle alone or may resort to placing children in institutional care.

2. Significant numbers of children with disabilities in Eastern and Southern Africa are placed in institutional care which is known to be harmful to children’s physical and psychological wellbeing and may have lifelong effects. Precise figures are impossible to obtain because data is infrequently collected and, when available, is typically partial. However, evidence from across the region shows that children with disabilities are often among the last to be included in deinstitutionalisation efforts, even though the detrimental impacts of institutionalisation are especially acute for boys and girls in these circumstances. Children with disabilities may be subjected to physical, sexual, verbal and emotional
abuse by staff, visitors and fellow residents\textsuperscript{19} (see Box 1). They also frequently experience life-threatening neglect and a lack of individualised attention and love and care, due to understaffing and the ignorance and negligence of employees.\textsuperscript{20} These experiences, and a lack of attention to rehabilitation whilst in institutional care, are known to exacerbate disability,\textsuperscript{21} further diminishing the ability of children to live within families or independently once they reach adulthood.

\begin{boxedquote}
\begin{quote}
Box 1: The indefinite segregation of children with disabilities in Kenya\textsuperscript{22}

A 2018 assessment found that families caring for children with disabilities face huge social and economic pressures to place their children in institutions. These facilities were generally deemed to be dangerous and often life-threatening settings. Boys and girls were found in overcrowded, filthy conditions, in restraints or isolated for long periods, neglected and ignored by staff who – sometimes willfully, or out of ignorance – denied them care and protection. The study argues that most of these children will face harm for their entire lives, either because they will never leave residential care or as a result of the ongoing consequences of having been placed there.
\end{quote}
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3. Domestic adoption and foster care are rarely available to children with disabilities. With a few notable exceptions, these care options are not well established in many settings in Eastern and Southern Africa, especially for children with disabilities.\textsuperscript{23} This is due to general government under-investment in family-based care, coupled with harmful beliefs and a lack of knowledge and understanding of disability among the general public, social care professionals and policy makers.

4. The provision of proper, supportive care for children with disabilities is a moral, economic, and legal imperative. Boys and girls with disabilities have the same rights as any other children, rights that are enshrined in the UN Convention on the Rights of the Child,\textsuperscript{24} the UN Convention on the Rights of Persons with Disabilities,\textsuperscript{25} the Guidelines for the Alternative Care of Children\textsuperscript{26} and in national legislation and standards across the region. Under these instruments, quality family-based care must be made equally accessible to all so that children with disabilities can grow up safe and protected in loving homes. Both the Committee on the Rights of the Child and the Committee on the Rights of Persons with Disabilities have identified the lack of care for children with disabilities as a problem in several countries in the region.\textsuperscript{27} The widespread use of institutional care for children with disabilities contravenes rights, is expensive and hinders efforts to end the use of institutional care for all children.

\section*{How should systems of child protection and care be enhanced to support the care of children with disabilities?}

- Develop an inclusive vision of care reform and prioritise the needs of children with disabilities and their families. Care reform should be guided by an over-arching strategy which sets out a clear vision and set of priorities for reform and provides details of the steps in the reform process. Comprehensive national strategies should include detailed reference to how the needs of children with disabilities will be addressed. Inclusive care reform as outlined by a care reform strategy must then be properly resourced.
Box 2: Inclusive care reform in Kenya

Kenya’s National Care Reform Strategy (2021) 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 the following.

- Campaigns to tackle false information about and stigma against children with disabilities.
- The registration of children with disabilities to ensure targeted services can be appropriately planned and 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.
- Capacity building of social workers in relation to disability.

- **Enact and enforce legislation and develop guidance, including for case management.** Take action to eliminate discrimination against children with disabilities and prioritise their inclusion in all aspects of life, regardless of type of impairment. Reference to disability should be made in all policies, laws and guidance on care, including case management guidance (see Box 3 for example).

Box 3: The Government of Rwanda’s Operational Guidance on Inclusive Children’s Reintegration

In 2021, the Government of Rwanda produced detailed case management guidance for the reintegration of children from residential institutions to family-based care. This document includes specific guidance to ensure that all children with disabilities live and flourish with their own family or in family-based alternative care. The guidance covers the following.

- Understanding disability and its different types and effects.
- Preparing a child with disabilities and their family for reintegration.
- How to engage with a child with a disability and speak with their family and siblings.
- How to conduct a home assessment.

The guidance can be found [here](#). Prior to the COVID-19 pandemic, 17 children with disabilities were reintegrated into families using this guide. During the COVID-19 lockdown, 348 children with disabilities were sent home from institutional care due to fears of COVID-19 infection. All of these children were assessed and assisted using this tool.

- **Build the capacity of social workers, including para-professionals and community volunteers.** Social workers and other professionals need to be made aware of the importance of addressing disability in care reform and to have some basic knowledge of disability and how it may affect children’s care. Training may be needed so that they can better support families to care for children with disabilities and avoid placement into institutional care. This may include training around gatekeeping mechanisms, case management guidance, existing disability-related services and support and referral mechanisms. Explicit efforts to change discriminatory social norms among social workers may also be necessary, as may capacity building around recognising signs or identifying children with disabilities as not all disabilities are visible and/ or obvious.
As part of the care reform process in Rwanda, social workers across the country have all received training on how to support children with disabilities and their families. Materials and trainings have been developed for para-professionals and community volunteers; these will be rolled out imminently. The content of the training varies slightly according to the target group, but generally covers the following topics.

- What is inclusion, and why does it matter for children with disabilities?
- Types and effects of disability among children.
- Why the words we use to talk about disability are important.
- Inclusive case management for child reintegration, and familiarisation with the forms and paperwork that are required.

**Box 4: Training social workers and community volunteers in Rwanda**

**Box 5: Changing social norms to support foster care for children with disabilities in Uganda**

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.
Once foster carers are recruited, Ekisa assesses children with disabilities and foster carers so that appropriate matches can be made that meet the child’s needs. This work is undertaken by social workers, who deeply examine each individual child’s specific requirements, and assess foster carers’ capacity to meet these needs. Where there are gaps, Ekisa works to identify supports that could be provided to foster carers. This might, for example, include fitting an accessible toilet to a house. Once a child is placed with a family, Ekisa provides follow-up monitoring and support.

- **Engage children, care leavers, parents and organisations of persons with disabilities.** It is important to listen to children with disabilities and to make continued efforts that enable them to take part in consultative processes. Likewise, networks and organisations of persons with disabilities should also be meaningfully consulted and involved.

**Box 6: Supporting children with disabilities to be their own advocates in Kenya**

The Kenya Society for Care Leavers (KESCA) is ramping up its efforts to amplify the voices of children and young people with disabilities who are living in, or have left, institutional care. To support this process, KESCA has care leavers with disabilities in senior positions within the organisation. It also supports young care leavers with disabilities to advocate at various national and international fora. Their primary message for policy makers, NGOs, and service providers is that, although children with disabilities share many of the same needs and experiences as other children, special attention needs to be paid to the specific challenges that confront this group of boys and girls. For example, it can be especially challenging for children and young people with disabilities to leave institutional care due to the lack of services and support in the community, and discrimination and rejection by families and communities. Maximum efforts must be made to support reintegration and aftercare for children and young people with disabilities. Those with disabilities trapped in residential care into adulthood are often especially disempowered and need extra support to have their voices heard.

- **Recognise diversity within the broad category of children with disabilities.** It is important to acknowledge the range of disabilities and the diversity of experiences of children and families in different contexts and circumstances, including how experiences are shaped by type of disability, level of social acceptance, gender, age, poverty, and other factors.

- **Develop a range of services and support.** Support and services are needed to enable children to remain in and return to families, and to be cared for well by parents and other caregivers. A range of high quality, family-based alternative care services are also needed for children who cannot be looked after by families. In some cases, this requires adjusting and expanding existing services to make sure they are inclusive. In other instances, new services may need to be developed. These services and support are outlined in detail in the next section. An underlying principle for all services for children with disabilities is that these children should not be segregated from other children.
What services and support do children with disabilities and their families need?

- Develop and implement gatekeeping mechanisms that bring together professionals to jointly make determinations and decisions about children’s care and support needs. Those involved in decision making about care need to understand the requirements of children with disabilities and their families. Decisions about care should be based on detailed assessments to ensure that households, families and children are given the support they require. Efforts should be directed towards finding the best fit for a child and a family, depending on individual needs, capacities and available resources. Placement decisions need to be guided by the goal of supporting children to have the best quality of life possible.

- Enable children to be cared for well in families. Families need a range of support and services to provide children with disabilities with safe and nurturing care at home, such as help making their home accessible, support with day and respite care, and family resource centres. The provision of inclusive quality education is also vital as a key reason for placement into institutional care is to access education that is otherwise unavailable or inaccessible for children with disabilities. It is also especially important to target social protection and other poverty alleviation programmes to children with disabilities and their families. These families may face higher costs for services such as health care, and may be unable to work due to caregiving responsibilities. Ensuring that multi-sectoral support is coordinated to avoid gaps in provision and to ensure that assistance is adapted to the changing needs of children and families is critical.

Box 7: The Harmonized Social Cash Transfer Programme (HSCT) in Zimbabwe

The HSCT is an unconditional social cash transfer that aims to improve the wellbeing of poor and vulnerable families living in the poorest households in Zimbabwe, including those with children with disabilities. By enhancing household incomes, the transfer seeks to support improved health, nutrition and education levels, particularly for children. Prior to cash disbursements, social service and child welfare offices share information on child protection, disability and HIV issues and together develop coordinated plans to assess, support and follow up on cases through the HSCT delivery and monitoring mechanisms. An evaluation of the programme conducted in 2015 found that the transfer helped to relax familial financial constraints and to strengthen existing social networks, including increasing informal sharing arrangements within the community, which can free up time for parents to work or to have some respite from their caring responsibilities.

- Make a range of quality alternative care options available for children with disabilities. These options may include kinship care, foster care, or supervised independent living. In line with global guidance, kinship care should always be explored as an option, and maximum efforts must be made to support extended family members or friends of the family to care for children with disabilities when parents cannot. Although not widely available in the region, there are examples of promising practice in relation to foster care for children with disabilities that illustrate the potential of this form of care (see Box 5 above). For older children and young people, particularly those preparing to live independently as adults, a period living alone or in groups in communities, supervised and supported by social workers and
community members, may be of value. All children with disabilities living in alternative care or recently reintegrated into families need to be carefully monitored and supported by social workers.

- **Reintegrate children with disabilities from alternative care back to families, and close or transform residential care facilities.** Where possible and in the child’s best interest, children with disabilities in alternative care should be reintegrated with families. Box 3 above provides an example of guidance on reintegration for children with disabilities in Rwanda. Once boys and girls have been reintegrated or placed into other forms of alternative care, residential care facilities for children with disabilities can either close or transform into centres providing other services such as foster care or family and community supports. The Ekisa Ministry in Uganda outlined in Box 5 is an example of one such transition as this organisation previously focused on the provision of residential care for children with disabilities.

- **Support care leavers with disabilities.** Care reform efforts need to recognise and support not only the needs of those who require reintegration from institutional to family-based care, but also those who go on to live independently as young adults. Equally important is the need to consider and find ways of supporting those young people who continue to reside in institutional care because family placements have not yet been found for them and independent living arrangements have not been considered or planned for (See Box 6 above).

- **Carefully consider the use of small group homes for children with disabilities.** As noted above, there is overwhelming evidence that large-scale institutional care should be used as a last resort for all children, including those with disabilities. However, debates remain over the use of smaller residential care facilities (sometimes called “small group homes”), where there is greater potential for children to receive high quality individualised care. Many experts argue that children with disabilities should never be placed in such facilities and are always better off in family-based care. Those who support this view include the Committee on the Rights of Persons with Disabilities and the UN Special Rapporteur on the Rights of Persons with Disabilities. Others make the case for a limited role for short-term small group residential care, particularly for children who are transitioning from institutional to family-based care or to living independently. Overall, there is agreement that maximum efforts must be made to ensure that children with disabilities can be cared for within safe and nurturing families. If small group homes do continue to be used, care must be taken to ensure that these residential facilities do not merely replace long-term care in large-scale institutions and that concrete plans are made for reintegration. Investments in small group homes should not come at the cost of investments in community-based support services.

- **Ensure that adoption services are available for children with disabilities.** Although domestic adoptions remain few in number in the region, there are examples of successful adoption services for children with disabilities. Inter-country adoption (ICA) is used on a small scale throughout Eastern and Southern Africa, including for children with disabilities. UNICEF supports the use of ICA as long as it is line with the Hague Convention on the Protection of Children and Cooperation in Respect of Inter-Country Adoption. Over the past two decades, some countries in the region temporarily suspended ICA to enable the conditions of the Convention to be met. Arguments have been made for the more widespread use of ICA for children with disabilities, given the dearth of quality care options for these groups in lower income countries. Many experts have disputed these suggestions, highlighting instead the need for the subsidiarity principle in the Hague Convention to be put into practice. This stipulation states that care and protection in-country must be improved to reduce the need for inter-country adoption for all groups.
Conclusion

The care of children with disabilities must be at the heart of child care reform efforts in Eastern and Southern Africa. Inadequate and often non-existent services and support, as well as stigma and discrimination, often lead to poor care within families, and many children are placed into harmful institutions where they are deprived of their rights. Boys and girls with disabilities do not have the same range of care options open to them as other children, and are often the last to be de-institutionalised. The inadequate care of these children contradicts global guidance on child rights, children's care and disability.

Supporting the better care of children with disabilities means explicitly and extensively considering disability in policies, legislation and guidance on care, including in relation to case management. Social workers, para-professionals and volunteers must be trained on the social model and human rights-based approach to disability. Children and care leavers with disabilities, their families and wider communities should all be engaged in reform efforts, and harmful social norms must be challenged. Policies and programmes should be guided by data, and more research is needed to fill substantial gaps in understanding on the care of children with disabilities in the region.

Children with disabilities and their families need a range of services and support. Priority should be given to supporting families to care for children with disabilities well. Doing so requires coordinated efforts from those working on disability, child protection, education, health and social protection. Foster care and adoption services should be adjusted to meet the needs of children with disabilities. Efforts should be made to close or transform residential care facilities, particularly large-scale institutions, and to reintegrate children with families. Care must be taken regarding the use of small group homes, especially if they are emphasised at the expense of community-based support services. Gatekeeping is needed to determine the best forms of care for each child and necessary support, and those involved in these mechanisms should also be properly trained in disability issues.


4 World Health Organization 2011, p.29.

5 Only a small handful of reports and assessments are in the public domain, and many of these are out of date. For example, the most comprehensive compilation of statistical data on children and adults with disabilities was published in 2011, when the World Health Organization published the first World Report on Disability. This point is also emphasised in UNICEF (2013) The state of the world’s children: Children with disabilities. New York: UNICEF.


9 These four reasons are clearly laid out in Better Care Network and EveryChild 2012.


15 BCN and EveryChild 2012.


17 From discussions with UNICEF country offices across the region.


21 BCN and EveryChild 2012.

22 Disability Rights International and Kenya Association for the Intellectually Handicapped 2018.


26 The Guidelines and the importance of family-based care for children with disabilities were further endorsed by the 2019 UN General Assembly resolution on the rights of the child. See: https://bettercarenetwork.org/sites/default/files/2020-01/A_RES_74_133_E.pdf

27 For example, with respect to Ethiopia, in 2016 the Committee on the Rights of Persons with Disabilities (CRPD) noted with concern the inadequate availability of community-based support for families with children with disabilities and parents with disabilities, and recommended that Ethiopia ensure the availability of community-based support for parents with disabilities and families with children with disabilities to guarantee enjoyment of the right to family on an equal basis with others. http://docstore.ohchr.org/Shared/PvtOffice/Files/Handler.ashx?enc=6QkG1d%2FPPPRiCAghkt7yhsps2gZ2dXWBKA18z%2F5v%2FbkY/0cl9z5id5%2BUAXK6vPAU76yrAw5yGr3%2BDAISC4b6K90c5f5fSy3 eaP6uZLrunvdv%2BuczMkxx7omG (paragraphs 49-50). With respect to Eritrea, in 2015 the UN CRC Committee’s recommendations included the need to continue to prioritise and promote the provision of family and community-based forms of alternative care for children deprived of parental care for any reason, including children with disabilities, in order to reduce the dependence on institutional care. https://www.refworld.org/country,CRC,ERI,566fbf7a4,0.html (paragraphs 49-50). With respect to Uganda, in 2016 the CRPD Committee recommended that legislation be enacted that prohibits the separation of children from their parents on the basis of the disability of either the child or one or both of the parents, and ensures support to families with persons with disabilities for raising their children at home. https://www.refworld.org/publisher,CRPD,UGA,57038e3c4,0.html


31 The training guides for different groups are currently being finalised and will be available on the Government of Rwanda’s website for open access later in 2021.

32 From interviews with Ekisa Ministry staff.

33 From interview with KESCA.

34 The Washington Group/UNICEF Module on Child Functioning, finalised in 2016, is a tool for assessing functional difficulties in children ages 2-17 years in different domains including hearing, vision, communication/comprehension, learning, mobility and emotions. See https://data.unicef.org/resources/module-child-functioning/

35 For more information on support, see the report by the UN Special Rapporteur on the Rights of Persons with Disabilities on support services for people with disabilities (pg.5-10): https://www.ohchr.org/Documents/Issues/Disability/A.HRC.34.58_Easy_to_read_version.pdf


40 https://www.unicef.org/media/intercountry-adoption

41 https://assets.hcch.net/docs/77a12123-d3dc-4851-8f0b-050f71a16947.pdf