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# Changing THE WAY WE *care*<sup>SM</sup>

Disability measurement in residential  
care facilities in Kenya and its role within  
case management



Changing The Way We Care<sup>SM</sup> (CTWWC) is implemented by Catholic Relief Services and Maestral International, along with other global, national and local partners working together to change the way we care for children around the world. Our principal global partners are the Better Care Network and Faith to Action. CTWWC is funded in part by a Global Development Alliance of USAID, the MacArthur Foundation and the GHR Foundation.

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## LIST OF ABBREVIATIONS

APDK	Association for the Physically Disabled of Kenya
CBO	Community-based Organization
CCIs	Charitable Children’s Institutions
CFM	Child Functioning Module
CTWWC	Changing the Way We Care
DCS	Department of Children’s Services
EARCs	Education Assessment Resource Centers
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health Child and Youth version
JH-IIRU	Johns Hopkins International Injury Research Unit
LIPs	Local implementing partners
LMICs	Low-and-middle-income countries
MDS	Model Disability Survey
MICS	Multiple Indicator Cluster Survey
NACOSTI	National Commission for Science, Technology & Innovation
NCCS	National Council of Children Services
NCPD	National Council for Population and Development
NGO	Non-Governmental Organization
SCIs	Statutory Children's Institutions
SW	Social Worker
UNICEF	United Nations Children’s Fund
WG	Washington Group on Disability Statistics
WHO	World Health Organization

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## EXECUTIVE SUMMARY

### **Alternative care**

Alternative care refers to non-traditional family-based or residential care for children when they are deprived of parental care. It is estimated that between 3.2 and 9.4 million children reside in institutional-type residential care settings globally. Most commonly, children enter residential care due to a combination of factors that may include natural disaster, poverty, abuse, neglect, or risks to safety. Introduction to residential care is also associated with low household income, lack of access to basic services (e.g., education), disability, and/or parental challenges.

Decades of research on the experiences of children in residential care suggest that residing in institutional care can negatively impact the health and well-being of children. Observed negative consequences include disrupted physical growth, hearing and vision problems, motor skill delays, and increased sickness. Children in residential care are also at risk of physical and sexual abuse by their staff and peers at higher rates than children in family settings. Research has also revealed that children in residential care settings suffer from cognitive, emotional, and social development stunting in addition to physical. Emotional abuse and neglect can also be common in residential care settings. Some research has shown that there can be positive outcomes relating to children's physical and emotional well-being.

Though research has been conducted on children with disabilities and on children in residential care settings, the intersections of these two topics has yet to be explored in depth. Notably, there is a lack of information surrounding disability measurement within residential care settings, highlighting a gap in the literature. It is estimated that a child with a disability is 17 times more likely to be placed in an institutionalized care setting than a child without a disability, and girls are more likely to be placed in an institution than boys.

### **Alternative care in Kenya**

As of 2014, it was estimated that 2.6 million children were without parental care in Kenya, many residing in residential care facilities. Kenya's formal residential care facilities are known as Charitable Children's Institutions (CCIs) and Statutory Children's Institutions (SCIs). Instances of abuse and mismanagement within residential care facilities are frequent; thus, the Kenyan government issued a moratorium on the registration of new CCIs in 2017 and in 2022 launched a National Care Reform Strategy to help strengthen families and promote family-based alternative care.

Among the children in residential care settings in Kenya, the most common reasons for admission were destitution, abandonment, and neglect, and the majority had experienced maltreatment. Orphanhood, violence, abuse, poverty, and lack of access to education were additional reasons cited. Research shows that children are less likely to have basic needs met in residential care, and findings from other Sub-Saharan African countries indicate that children in residential care are more likely to experience stunting and underweight. That said, experiences of children can vary dramatically between facilities.

Kenya has measured disability on a national level through the national census using the UNICEF/WG Questions. Kenya reported an overall disability prevalence of 2.2%, and this includes sight, hearing, mobility, cognition, self-care, and communication. However, due to the broad nature of the census questions, little is known about the prevalence of child disability within CCIs.

### **Disability measurement**

In 2000, UNICEF introduced a disability module for children through the Multiple Indicator Cluster Survey. In 2011, in collaboration with the Washington Group, UNICEF revised the initial module. The

new tool was based on the aforementioned ICF framework and helps users assess child functioning. It covers the following domains: seeing, hearing, walking, communication, learning, relationships, and playing. Later, the domains of emotion, behavior, concentration, and coping with change were added. It is applicable to children between 2-17 years of age. Field testing was conducted in several different countries and settings, and the final tool was used for this study.

### **Study aims and methodology**

This study was conducted as part of Changing the Way We Care (CTWWC), a global initiative on care reform, including in Kenya. The initiative seeks to influence key stakeholders – including governments, families of children living in residential care, and donors - to provide, safe, and nurturing family care for children and pathways for children in residential care to return to their families and communities. The purpose of this study was to pilot the measurement of disability amongst children in residential care in Kenya.

This was a mixed methods study comprising of a qualitative and quantitative phase. While the population of interest was children in residential care in Kenya, the respondents were key stakeholders involved in residential care policy development and service provision. The study was conducted in 18 residential care facilities in Nyamira, Kisumu, and Kilifi counties where CTWWC works in collaboration with the local implementing partners. The staff at these facilities had already received training and support in case management from CTWWC teams, amongst other forms of support.

During the qualitative phase, key informant interviews were conducted with government officials, and organizations of people with disabilities groups/councils to engage and learn more on local work around measurement of disability among children and potential gaps to address the needs of these children. The data collection for key informant interviews and in-depth interviews was conducted by the JHU consultants. A total of 20 key informant interviews were conducted with governmental officials, OPDs, protection services in Kenya.

The quantitative study involved implementing the CFM using cross-sectional study design. In the residential care facilities, data was collected by case managers through review of records and through discussions with primary caregivers in the residential care. There were 471 children residing in the participating residential care facilities in Kenya.

### **Findings**

The current policy environment has made it a priority to support children in need of care through development of various policies. While these policies look good on paper, the study participants shared that there are implementation gaps which preclude their full implementation and hence, have called for development of implementation processes relevant to Kenyan context.

Key informants identified various facilitators and barriers to support children with disabilities. These included factors associated at the policy level, residential care facility level, and family and community level. Facility staff recognized that the facilities are dependent on community partnerships and government level engagements to provide these services and cannot function on their own. Stakeholders identified solutions that could be implemented simultaneously at policy and community levels to strengthen the system for children with disabilities. These varied from sensitization of various government entities and communities to drawing upon learnings from another context. The key stakeholders also recognized the importance of have data to support implementation and monitoring of these solutions.

In Kenya, children in residential care come from different social backgrounds and some from traumatic experiences. Their needs vary and case management plans for each child needs to be unique and customized. The residential care facilities studied are limited in their capacity to provide care to the children despite the compassion felt by the facility staff towards children with disabilities. This is mainly due to limited human resources which is compounded by limited financial resources available to the facilities to function. Facility staff indicated the need for developing capacity of the facility and its members to be able to work with and support children with functional limitations and disabilities. They indicated that in addition to having tools and resources for early identification and referrals, trainings and linkage to community-based efforts are needed to reduce stigma associated with disability.

Overall, the facility staff found the child functioning module (CFM) to be an easy tool to use, although there is a learning curve associated with its use as part of the case management processes. The benefits of the tool were noted not only at the facility level but beyond including at the community level to support reunification and longer-term reintegration of children into their families and communities.

The two version of the CFM tools were implemented in a total of 18 facilities across the three counties in Kenya. The breakdown of the number of children in the two age groups across the three counties is provided below. It shows that majority of children living in the residential care at the time of this study were between the ages of 5-17 years.

Among children between 2-4 years of age, 42% had mild functional limitation, while 4% had severe functional limitation. No difficulty was reported for seeing, hearing, understanding by caregiver, or being understood by caregiver. The majority of the children had mild difficulty in controlling behavior, playing, fine motor movements, and walking. Severe learning difficulty was reported for one child. Among children between 5-17 years of age, 19% had mild functional limitation, 6% had moderate functional limitation while 4% had severe functional limitation. The majority of the children had functional limitation in the domains of learning, remembering, concentrating, accepting change, controlling behavior, and making friends. Among children with moderate and severe functional limitation, the percentage of female children was higher compared to male children.

### **Conclusions and recommendations**

This study found that residential care facilities are not disability-friendly, staff lack necessary skills to understand and work with children with disabilities and improving this is not a priority. Effort needs to be put into training the social service workforce, updating tools and methodologies for case management, and establishing referral networks. Awareness raising and service capacity building, by way of improved tools, resources, and skills, will improve families' and communities' ability to care for their children and likely reduce stigma. These are services that residential care facilities could consider providing as they transition towards family care and away from residential models, as foreseen in the National Care Reform Strategy.

Given the implementation and endorsement of care reform at the national level in Kenya, this study provides an opportunity to engage with the government to ensure that children with disabilities are not left behind and that tools like the CFM are part of the case management toolkit. The government can play a key role in supporting implementation and monitoring of policies by investing in data systems and key indicators. Beyond Kenya, this study provides comparable data that could be used across other contexts where CFM is being used in alternative care, an opportunity to contribute towards the global momentum on supporting better care for children, without leaving those with disabilities behind.



## LITERATURE REVIEW

### Children in alternative care

Alternative care can be provided formally or informally, where *formal care* describes care which has been ordered by a competent administrative body or judicial authority, while *informal care* is “any private arrangement provided in a family environment without this arrangement having been ordered by an administrative or judicial authority or a duly accredited body”.<sup>1</sup> Alternative care can be family-based or residential. Residential care is defined as a publicly or privately managed living arrangement for children that is not family-based.<sup>2</sup> Children are placed in residential care when deprived of parental care, and such facilities include any kind of group alternative care, institutions, group homes, “children’s homes” and “orphanages.”<sup>1</sup>

A 2020 estimation study on the number of children currently residing in institutional-type residential care, revealed a median estimate of 5.4, a global prevalence estimate of 7.5 million with a range from 3.2 to 9.4 million children.<sup>3</sup> While the median is likely an underestimation due to poorly developed definitions and monitoring mechanisms in some countries, the systematic review conducted by Desmond and colleagues employed a robust methodology and reflects one of the most accurate estimations of children in residential care to date.<sup>3</sup> The study also presents regional estimates (pre-COVID), and the smallest root-mean-square errors method approximates that there are 1.13 million children living in institutional-type residential care in South Asia, 650,000 in Sub-Saharan Africa, 230,000 in Latin America, and 90,000 in North America.<sup>3</sup>

There are any number of risk factors that increase a child’s chance of entering alternative care, and residential care, in particular. These risk factors can present at the individual, family, peer, school, or community/neighborhood level.<sup>4</sup> Most commonly, children enter residential care because of a combination of factors and after natural disaster, poverty, abuse, neglect or risks to their safety.<sup>5,6,7</sup> Entering care is associated also with low household income, lack of access to basic services like education, disability, teen pregnancy and/or single motherhood, parental unemployment, and/or parental relationship breakdown.<sup>8</sup>

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<sup>1</sup> United Nations General Assembly 64th session. Guidelines for the Alternative Care of Children: resolution / adopted by the General Assembly. 2010Feb24:1-23

<sup>2</sup> Goldman PS, Bakermans-Kranenburg MJ, Bradford B, Christopoulos A, Ken PLA, Cuthbert C, et al. Institutionalisation and deinstitutionalisation of children 2: policy and practice recommendations for global, national, and local actors. *The Lancet Child & Adolescent Health*. *The Lancet Child Abuse & Adolescent Health*; 2020;4(8):606-633.

<sup>3</sup> Desmond C, Watt K, Saha A, Huang J, Lu C. Prevalence and number of children living in institutional care: global, regional, and country estimates. *The Lancet Child & Adolescent Health*; 2020;4(5):370-377

<sup>4</sup> Aguilar M, Roshani M, Hassanabadi H, Masoudian Z, Afruz G. Risk and protective factors for residential foster care adolescents. *Children and Youth Services Review*. *Children and Youth Services Review*; 2010;33(1) 1-15

<sup>5</sup> Sattler KMP, Font SA, Gershoff ET. Age-specific risk factors associated with placement instability among foster children. *Child Abuse & Neglect*. *Child Abuse & Neglect*; 2018; 84:157-69

<sup>6</sup> Morantz G, Cole DC, Ayaya S, Ayuku D, Braitstein P. Maltreatment experiences and associated factors prior to admission to residential care: A sample of institutionalized children and youth in western Kenya. *Child Abuse & Neglect* [Internet]. *Child Abuse & Neglect*; 2013;37(10):778-87. Available from: <https://dx.doi.org/10.1016/j.chiabu.2012.10.007>

<sup>7</sup> Lancet Group Commission. Institutionalisation and deinstitutionalisation of children: the Executive Summary from a Lancet Group Commission. *The Lancet Child & Adolescent Health*;2020;4(8):562-563. Available from: [https://doi.org/10.1016/S2352-4642\(20\)30089-4](https://doi.org/10.1016/S2352-4642(20)30089-4)

<sup>8</sup> Jones R, Everson-Hock ES, Papaioannou D, Guillaume L, Goyder E, Chilcott J, et al. Factors associated with outcomes for looked-after children and young people: a correlates review of the literature. *Child: Care, Health,*

### Documented negative outcomes:

Decades of research suggests that residential care, including large scale institutional care and small group homes, can have a negative impact on a child's health and well-being.<sup>9</sup> The care, particularly that in large-scale institutions is often inconsistent, and because children are not always provided with an appropriate environment or adequate levels of caregiving and basic resource needs, they may suffer from stunted physical, cognitive, emotional, and social development.<sup>7,9</sup> Children are also at risk of maltreatment from staff and their peers by way of physical and sexual abuse, at higher rates than children in families.<sup>7,9</sup>

*Physical development:* A child's surrounding environment plays a large role in their physical development. In institutions, children tend to have less access to space, limited toys, and reduced play. As a result, their experiences can be over-controlled, causing detrimental harm.<sup>10</sup> Some risks include disrupted physical growth in terms of height, weight, and head circumference.<sup>11</sup> They may also have hearing and vision problems due lack of stimulation, motor skill delays that lead to physical and learning disabilities, and increased sickness.<sup>12</sup> Physical effects can also be seen in hormonal underdevelopment, as seen in the atypical patterns of diurnal cortisol activity first reported in 1997.<sup>13</sup> Sometimes, the facilities cause sleep deprivation, which exacerbates other negative outcomes.<sup>14,15</sup> Lastly, children in residential care are at higher risk for physical violence in the facility, including but not limited to beatings, sexual violence, and child labor.<sup>16</sup>

*Cognitive development:* There are long-lasting cognitive and psychological consequences that may occur because of institutionalization, and these have been well documented in the literature.<sup>11,16</sup> Due to a lack of adequate stimulation, children may suffer from impaired intellect and language deficits, as well as other delays in brain development.<sup>11</sup> A systematic review of literature on experiences in residential care revealed that almost all existing studies found children in residential care to experience cognitive

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and Development [Internet]. Child: Care, Health, and Development; 2011;37(5):613-22. Available from: <https://dx.doi.org/10.1111/j.1365-2214.2011.01226.x>

<sup>9</sup> Better Care Network. Effects of Institutional Care [Internet]. Better Care Network. 2021 [cited 2021Jan14]. Available from: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/effects-of-institutional-care>

<sup>10</sup> Lynch T, Hempel R, Dunkley C. Radically Open-Dialectical Behavior Therapy for Disorders of Over-Control: Signaling Matters. The American Journal of Psychotherapy [Internet]. The American Journal of Psychotherapy; 2015; 69(2):141-62. Available from: <https://doi.org/10.1176/appi.psychotherapy.2015.69.2.141>

<sup>11</sup> Van Ijzendoorn MH, Palacios J, Sonuga-Barke EJS, Gunnar MR, Vorria P, Mccall RB, et al. I. CHILDREN IN INSTITUTIONAL CARE: DELAYED DEVELOPMENT AND RESILIENCE. Monographs of the Society for Research in Child Development [Internet]. Monographs of the Society for Research in Child Development; 2011;76(4):8-30. Available from: <https://dx.doi.org/10.1111/j.1540-5834.2011.00626.x>

<sup>12</sup> Browne K. The Risk of Harm to Young Children in Institutional Care. Save the Children [Internet]. Save the Children. 2009 [cited 2021Jan14]. Available from: [http://learn.viva.org/wp-content/uploads/2017/08/The\\_Risk\\_of\\_Harm.pdf](http://learn.viva.org/wp-content/uploads/2017/08/The_Risk_of_Harm.pdf)

<sup>13</sup> Carlson M, Earls F. Psychological and neuroendocrinological sequelae of early social deprivation in institutionalized children in Romania. Annals of the New York Academy of Sciences [Internet]. Annals of the New York Academy of Sciences; 1997;807:419-428. Available from: <https://doi.org/10.1111/j.1749-6632.1997.tb51936.x>

<sup>14</sup> Dobson R, Klotz S. From a whisper to a shout: a call to end violence against children in alternative care. SOS Children's Villages International, University of Bedfordshire [Internet]. SOS Children's Villages International, University of Bedfordshire. 2015 [cited 2021Jan14]. Available from: <https://resourcecentre.savethechildren.net/node/8865/pdf/from-a-whisper-to-a-shout-a4-en-web-final.pdf>

<sup>15</sup> Pinheiro S. Violence Against Children in Care and Justice Institutions. In: World Report on Violence against Children. United Nations Secretary-General's Study on Violence against Children.; 2006

<sup>16</sup> Sherr L, Roberts KJ, Gandhi N. Child violence experiences in institutionalised/orphanage care. Psychology, Health & Medicine [Internet]. Psychology, Health & Medicine; 2017;22(sup1):31-57. Available from: <https://dx.doi.org/10.1080/13548506.2016.1271951>

deficits. Additionally, a meta-analysis conducted in 19 countries revealed lower IQ values among children in residential care than those in family-based care.<sup>11,16</sup>

*Emotional development:* Emotional abuse and neglect can be common in residential care, including instances of verbal abuse, ridicule, degradation, humiliation, and psychological domination or control.<sup>14,16</sup> The lack of interaction and isolation from community and family can result in emotional attachment disorders.<sup>15</sup> Additionally, the structure of residential care facilities is such that children are often cared for away from community and by multiple providers, which hinders their ability to form secure emotional attachments to a consistent caregiver.<sup>17</sup>

*Social development:* Residential care may result in a lack of interaction with others and therefore stunted social behavior.<sup>14,15</sup> The resulting environment of isolation and confinement is detrimental to social development.<sup>14</sup> Some consequences include behavioral problems, lack of life skills, attachment disorders, and difficulty forming and maintaining healthy relationships.<sup>14</sup> Bullying is also a well-documented issue in residential care that can have lasting effects on social development.<sup>15</sup>

#### **Documented positive outcomes:**

While the bulk of prior research converges on the negative consequences of living in residential care, recently, long-term studies of children in residential care have also found positive outcomes relating to physical and emotional well-being. The Positive Outcomes for Orphans study, which focused on Cambodia, Ethiopia, India, Kenya, and Tanzania, found that children in residential settings performed better on assessments of physical and emotional well-being measures than their family-based counterparts. These findings suggest that with appropriate caregiver attention, organization, and educational components, children can do well in some areas of development and in some non-family-based settings.<sup>18</sup>

#### **Implications of separation from the community:**

Care leavers, young people who grew up in alternative care, continue to experience negative effects of residential care following their reintegration into society.<sup>19</sup> Without kinship or community networks nor federal programs to provide social and financial support, care leavers are often left with nowhere to

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<sup>17</sup> Slopen N, McLaughlin K, Fox N, Zeanah C, Nelson C. Alterations in neural processing and psychopathology in children raised in institutions. *Archives of General Psychiatry* [Internet]. *Archives of General Psychiatry*; 2012; 69:1022-1030. Available from: <https://doi.org/10.1001/archgenpsychiatry.2012.444>

<sup>18</sup> Forum on Investing in Young Children Globally; Board on Global Health; Board on Children, Youth, and Families; Health and Medicine Division; Division of Behavioral and Social Sciences and Education; National Academies of Sciences, Engineering, and Medicine. *The Effects of Institutionalization and Living Outside of Family Care on Children's Early Development. Reaching and Investing in Children at the Margins: Summary of a Joint Workshop by the National Academies of Sciences, Engineering, and Medicine; Open Society Foundations; and the International Step by Step Association (ISSA)*; 2016. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK373333/>

<sup>19</sup> Ucembe S. *Institutional Care for Children in Kenya* [Internet]. *Global Perspectives*. *Global Perspectives*; 2016. Available from: [https://www.researchgate.net/profile/Kwabena\\_Frimpong-Manso2/publication/317400935\\_Residential\\_Care\\_For\\_Children\\_in\\_Ghana\\_Strengths\\_and\\_Challenges/inks/5e7750ef299bf1892cff70bc/Residential-Care-For-Children-in-Ghana-Strengths-and-Challenges.pdf#page=185](https://www.researchgate.net/profile/Kwabena_Frimpong-Manso2/publication/317400935_Residential_Care_For_Children_in_Ghana_Strengths_and_Challenges/inks/5e7750ef299bf1892cff70bc/Residential-Care-For-Children-in-Ghana-Strengths-and-Challenges.pdf#page=185)

turn during their transition to independent life.<sup>18, 20, 21</sup> As a result, outcomes for this group are, on average, poorer as compared to the general population.<sup>22</sup> Reported challenges with the reintegration process include poor reception from society, difficulties securing housing and healthcare, and limited success in education and employment.<sup>19, 20, 21</sup> Many care leavers also report a lack of life skills such as cleaning, budgeting, and shopping, as well as basic networking and social skills.<sup>19, 20</sup> Some care leavers may require support in the areas of counselling services, housing security, health advice, job placement assistance, and home management in order to facilitate their transition back to community.

## Childcare system in Kenya

As of 2014, there were approximately 2.6 million children deprived of parental care in Kenya, almost 50% of which have been left so due to HIV/AIDS.<sup>23</sup> The precise number of children in residential care is unknown. One study estimated that 30-45% of the 2.6 million children without parental care reside in residential care facilities.<sup>24</sup> The Kenyan government has recently given figures of 45,000 children living in over 845 privately run facilities and a further estimated 1,000–1,200 children living in 28 government run institutions.<sup>25</sup> A child can enter the system through either a formal or informal channel. Placement can either be ordered by an administrative body or defined as a private arrangement.<sup>46</sup> Kenya's formal residential care facilities are called Charitable Children's Institutions (CCIs) and Statutory Children's Institutions (SCIs) such as rehabilitation, remand, reception, and rescue centers. As established by the Kenyan Children Act in 2001, institutions housing single or double orphans qualify as CCIs if they serve more than 20 children.<sup>45</sup> There are approximately 415 registered CCIs serving children in Kenya.<sup>45</sup> In an effort to address instances of abuse and mismanagement within residential care in Kenya, the Kenyan government announced a moratorium on the registration of new CCIs effective November 2017 and has launched a National Care Reform Strategy to develop family strengthening and family-based alternative care, and to reduce reliance on residential care.<sup>26</sup>

An analysis of CCIs in Western Kenya revealed that of 462 children in CCIs, the most common reasons for admission were destitution (36%), abandonment (22%), and neglect (21%), and the majority had experienced maltreatment (66%), highlighting the need for better child abuse and neglect prevention.<sup>19</sup> Other common reasons for placement were orphanhood, violence, abuse, poverty, and lack of access to education.<sup>27</sup> In an assessment of children's basic human rights in residential care settings in Kenya,

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<sup>20</sup> Hodgkinson K, Pouw NRM. The Social Exclusion of Vulnerable Youth Country Report: Guatemala. Amsterdam Institute for Social Science Research. 2017 [cited 2021May31]. Available from: [https://www.researchgate.net/profile/Katie-Hodgkinson/publication/321082123\\_The\\_Social\\_Exclusion\\_of\\_Vulnerable\\_Youth\\_Country\\_Report\\_Guatemala/links/5a0c6237aca2729b1f4d242d/The-Social-Exclusion-of-Vulnerable-Youth-Country-Report-Guatemala.pdf](https://www.researchgate.net/profile/Katie-Hodgkinson/publication/321082123_The_Social_Exclusion_of_Vulnerable_Youth_Country_Report_Guatemala/links/5a0c6237aca2729b1f4d242d/The-Social-Exclusion-of-Vulnerable-Youth-Country-Report-Guatemala.pdf)

<sup>21</sup> Cudjoe E, Amoateng I, Nti-Gyeabour J, Wisti P. Exploring the support services of foster care leavers: an institutional ethnographic study. *Health and Social Care in the Community*; 2020; 00:1-10.

<sup>22</sup> Liabo K, McKenna C, Ingold A, Roberts H. Leaving foster or residential care: a participatory study of care leavers' experiences of health and social care transitions. *Child: care, health, and development*; 2016; 43(2):182-191.

<sup>23</sup> Embleton L, Ayuku D, Kamanda A, Atwoli L, Ayaya S, Vreeman R, et al.. Models of care for orphaned and separated children and upholding children's rights: cross-sectional evidence from western Kenya. *BMC International Health and Human Rights*. *BMC International Health and Human Rights*; 2014; 14(1):9.

<sup>24</sup> Chege N, Ucembe S. Kenya's Over-Reliance on Institutionalization as a Child Care and Child Protection Model: A Root-Cause Approach. *Social Sciences* [Internet]. *Social Sciences*; 2020; 9(57).

<sup>25</sup> Government of Kenya. National Care Reform Strategy for Children in Kenya: 2022-2032; 2022.

<sup>26</sup> Better Care Network. Children's Institutions in Five Counties: Kiambu, Kilif I, Kisumu, Murang'a, and Nyamira Summary Report [Internet]. Better Care Network. 2020 [cited 2021Oct13]. Available from: <https://bettercarenetwork.org/library/the-continuum-of-care/residential-care/situational-analysis-report-for-childrens-institutions-in-five-counties-kiambu-kilif-i-kisumu-murang>

<sup>27</sup> Lombe M, Ochumbo A. *Children and AIDS: Sub-Saharan Africa*. Farnham, Surrey, England: Ashgate; 2016.

researchers found that children in residential care were significantly more likely ( $p < 0.0001$ ) to have basic needs met as compared to those in family settings.<sup>46</sup> Overall, residential care facilities more consistently achieved an adequate standard of living. This is consistent with findings from other sub-Saharan African countries.<sup>45</sup> Other studies have found contradicting results. A study of orphanage and non-orphanage children in Nairobi revealed that children in residential care were more likely to experience stunting and underweight ( $p < 0.05$ ) and had a higher morbidity rate ( $p < 0.05$ ) than children in family settings.<sup>28</sup> The polarity of results suggests that the experiences of children in residential care vary dramatically from facility to facility.

Despite the range of experiences, Kenyan CCIs are supposed to follow two legal frameworks outlining the care of children: Best Practice Standards for Charitable Children Institutions, developed in 2013, and the Guidelines for Alternative Care of Children in 2014.<sup>19</sup> Still, children in any residential care settings are at risk of potentially traumatic events and post-traumatic stress disorder through acts of bullying, physical abuse, and sexual abuse.<sup>49</sup> For future reform, community-based organizations and religious residential care facilities have potential to assist families and children in family-based care so that they can achieve an adequate standard of living, positive parenting, healthy attachments, and access to services.<sup>45</sup>

Kenya has measured disability on a national level through the national census. In 2019, Kenya reported an overall disability prevalence of 2.2%. This was the first Kenyan census to employ the Washington Group Short Set of Questions as its main method of assessment, measuring six capacities: sight, hearing, mobility, cognition, self-care, and communication. However, the findings are limited by the exclusion criteria; children under the age of 5 were omitted.<sup>50</sup> The absence of a reliable measurement approach for children with disability highlights a potential area for development. Furthermore, little is known about the prevalence of child disability within CCIs due to the broad nature of the census questions and the how people not normally resident within a household were included.<sup>29</sup>

### Measuring disability among children living in residential care

Separate research has been conducted on children with disabilities and children living in residential care, however evidence at the intersection of these topic areas remains scarce.<sup>30</sup> Many countries are unable to supply data on disability status of children, let alone those in care, and it is unclear whether this is due to a lack of administrative capacity and/or underdeveloped measurement approaches.<sup>31</sup> There is a glaring lack of work done on *measuring* disability in residential care, which reflects the gap in the literature.

In terms of what is known about the experiences of children with disabilities in residential care, it is documented that children with disabilities, in both developed and developing countries, widely inhabit residential care facilities. In some cases, parents are even encouraged to place their children into

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<sup>28</sup> Atwoli L, Ayuku D, Hogan J, Koech J, Vreeman RC, Ayaya S, et al. Impact of Domestic Care Environment on Trauma and Posttraumatic Stress Disorder among Orphans in Western Kenya. PLOS ONE [Internet]. PLOS ONE; 2014;9(3):e89937. Available from: <https://dx.doi.org/10.1371/journal.pone.0089937>

<sup>29</sup> Development Initiatives. Status of Disability in Kenya: Statistics from the 2019 Census. Development Initiatives. 2020. Available from: <https://devinit.org/resources/status-disability-kenya-statistics-2019-census/>.

<sup>30</sup> Kaminska A, Nadolska A, Blahutkova M, Slizik M. Evaluation of the nearest development zone for children with a light degree of intellectual disability who live in an orphanage. TRENDS in Sport Sciences. TRENDS in Sport Sciences; 2018;2(25):75-83.

<sup>31</sup> UNICEF. Orphans [Internet]. UNICEF. 2017 [cited 2021Jan14]. Available from: [https://www.unicef.org/media/media\\_45279.html](https://www.unicef.org/media/media_45279.html)

residential care upon diagnosis by professionals.<sup>32</sup> As a result, in some countries, children with disabilities are at a much higher risk of being institutionalized, as seen in the case of Eastern European countries where it is estimated that a child with a disability is 17 times more likely to be placed in an institution as a child who is not disabled<sup>25</sup> even after a decade or more of reform. Girls with disabilities are more likely to be placed in an institution than boys.<sup>25</sup> Girls and boys with disabilities are more likely to be sent to youth detention centers; it is estimated that up to 25% of children in such facilities have a disability.<sup>25</sup> Access to specialized services is also cited as a reason for sending a child into residential care by parents and caregivers in several country contexts.<sup>25</sup>

While measuring child disability in residential care settings has not been a focus of research, several studies have looked at the experiences of children with disabilities in residential care. A Human Rights Watch report on children with disabilities in Russian orphanages found that all 10 facilities they visited were plagued with child neglect and a lack of health care, education, and play. Many children were visibly underdeveloped or malnourished, lacked medical treatment and rehabilitation, received little to no academic instruction, and spent of their days with toys out of reach. Because of the lack of stimulation, health care, and education, the Russian children with disabilities were found to be severely physically and cognitively underdeveloped.<sup>33</sup> A similar study on children with disabilities in institutions in Nepal found significant evidence indicating an association between mental and physical disability and undernutrition (both wasting and stunting).<sup>34</sup>

In Bulgaria, children with disabilities are deliberately separated from society, which leads to continued segregation throughout their lives. Observation has shown that children in Bulgaria's group homes experience neglect, inappropriate models of behavior, violence, and bullying.<sup>35</sup> Similarly, Myanmar has "institution-based rehabilitation" that calls for the persistent institutionalization of children and adults with disabilities.<sup>36</sup> An assessment of the residential care facility landscape in Myanmar revealed that of the 147 facilities visited, 37% of the facilities had children with disabilities. Of the children with disabilities, 82% had physical disabilities. It is not specified how disability was measured.<sup>37</sup> According to a facility profile done in Zambia, 36.9% children in care were found to have a disability.<sup>38</sup>

A two-year investigation by Disability Rights International (DRI) into child care institutions in Kenya uncovered that not only were the basic living conditions poor, but many institutions were unregistered and housed children with no governmental oversight. The facilities for children with disabilities were

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<sup>32</sup> UNICEF. UNICEF Fact Sheet Children with Disabilities. 2022 [cited 2023Jan10]. Available from: <https://www.unicef.org/media/128976/file/UNICEF%20Fact%20Sheet%20:%20Children%20with%20Disabilities.pdf>

<sup>33</sup> Human Rights Watch. Abandoned by the state: violence, neglect, and isolation for children with disabilities in Russian orphanages. 2014 [cited 2021Jan14]. Available from: <https://resourcecentre.savethechildren.net/sites/default/files/documents/5416cec64.pdf>

<sup>34</sup> Fernández L, Rubini A, Soriano JM, Aldás-Manzano J, Blesa J. Anthropometric Assessment of Nepali Children Institutionalized in Orphanages. *Children*. 2020;7(11):217

<sup>35</sup> Better Care Network. A Dead End for Children: Bulgaria's Group Homes [Internet]. Better Care Network. 2019 [cited 2021Jan14]. Available from: <https://bettercarenetwork.org/sites/default/files/2019-11/Bulgaria-final-Nov19-web.pdf>

<sup>36</sup> Better Care Network. Country Care Review: Myanmar [Internet]. Better Care Network. 2019 [cited 2021Jan14]. Available from: <https://bettercarenetwork.org/sites/default/files/2019-10/Myanmar%20Country%20Care%20Review.pdf>

<sup>37</sup> UNICEF. The situation of children in residential care facilities in Myanmar [Internet]. UNICEF. 2011. Available from: <http://www.iccwtnispncanarc.org/upload/pdf/9954435570The%20Situation%20of%20Children%20in%20Residential%20Care%20Facilities%20in%20Myanmar.pdf>

<sup>38</sup> Factors Related to the Placement into and Reintegration of Children from Catholic-affiliated Residential Care Facilities in Zambia. [https://ovcsupport.org/wp-content/uploads/2016/10/CCC\\_Zambia\\_Layout\\_web.pdf](https://ovcsupport.org/wp-content/uploads/2016/10/CCC_Zambia_Layout_web.pdf)

even worse, and in many cases, dangerous and uninhabitable. Children with disabilities were kept in overcrowded, squalid rooms and were paid little to no attention from staff. Based on their assessment, DRI concluded that children with disabilities in Kenya are “intentionally left to die.”<sup>39</sup>

These studies share common findings. Children with disabilities who reside in large residential care facilities often suffer from neglect, cruel, inhumane, or degrading treatment from caregivers and staff. Violations cited by the UN Study on Violence Against Children include widespread violence and neglect, physical and medical restraint, and facilities being understaffed.<sup>25</sup>

While literature on measuring disability among children in residential care remains scarce, methods for measuring disability among children in other settings have been well documented. As seen in the World Health Organization and World Bank Model Disability Survey project (MDS), questionnaires can be tailored to target disability and health conditions in children in order to improve data collection on children with disabilities. The MDS also solicits additional information surrounding environmental and personal factors, emphasizing that disability is an outcome of interactions between several factors.<sup>40</sup> Most surveys of this nature are based on the Washington Group (WG) questions, which use the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health as a framework to measure disability.<sup>41,42</sup> The WG questions assess capacity for seeing, hearing, mobility, fine motor skills, self-care, communicating, learning, remembering, concentrating, playing, behavior, anxiety/depression, accepting chance, and relationships.<sup>33</sup>

## ICF-CY framework

The WHO modified the International Classification of Functioning, Disability and Health (ICF) framework and adapted it for children and youth (ICF-CY) to better understand needs of children with disability as they grow.<sup>43,44</sup> The framework comprises of health and health-related domains, and includes environmental factors. It provides common language to measure health and disability at both individual and population levels. To account for various physical, social and psychological development stages of children and youth, the ICF-CY framework accounts for these stages within child’s surrounding environment. Like ICF, ICF-CY assesses body functions and structures, limitations in activities, restriction

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<sup>39</sup> Rodriguez P, Ahern L, Bradshaw J, Kanter A, Koijiet M, Levy R, Miller MR, Rosenthal E, Wangare F. Infanticide and Abuse: Killing and confinement of children with disabilities in Kenya [Internet]. Disability Rights International. 2018. Available from: <https://www.driadvocacy.org/wp-content/uploads/Infanticide-and-Abuse.pdf>

<sup>40</sup> Sabariego C, Oberhauser C, Posarac A, Bickenbach J, Kostanjsek N, Chatterji S, et al. Measuring Disability: Comparing the Impact of Two Data Collection Approaches on Disability Rates. International Journal of Environmental Research and Public Health [Internet]. International Journal of Environmental Research and Public Health; 2015;12(9):10329–51. Available from: <https://dx.doi.org/10.3390/ijerph120910329>

<sup>41</sup> WG Short Set on Functioning (WG-SS) [Internet]. The Washington Group. [cited 2021Jan15]. Available from: <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

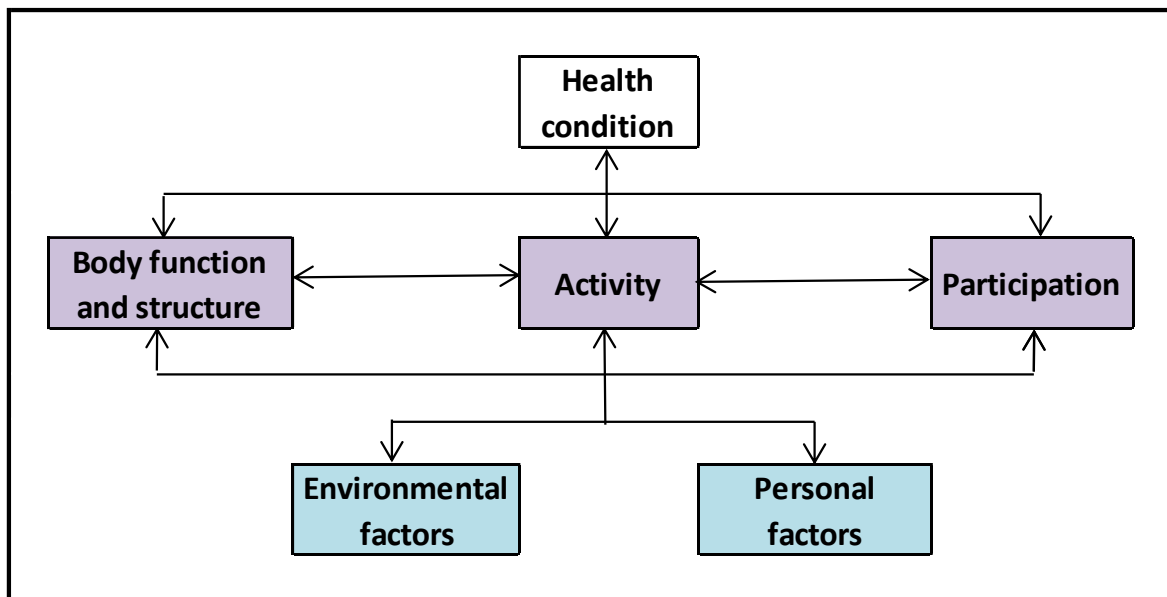
<sup>42</sup> Washington Group - Short Set of Questions on Disability [Internet]. Centers for Disease Control and Prevention. Centers for Disease Control and Prevention; 2015 [cited 2021Jan15]. Available from: [https://www.cdc.gov/nchs/washington\\_group/wg\\_questions.htm](https://www.cdc.gov/nchs/washington_group/wg_questions.htm)

<sup>43</sup> Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. BMC Public Health. 2011;11 Suppl 4:S3.

<sup>44</sup> UNICEF. The State of the World’s Children 2013: Children with Disabilities New York, USA: UNICEF; 2013 [Available from: <https://www.unicef.org/sowc2013/>]

in participation, and relevant environmental factors manifested during various developmental stages of children - infancy, childhood and adolescence.<sup>45</sup>

**Figure 1: Conceptual Framework for the International Classification of Functioning**



The framework was proposed in 2007 to account for disability in children which differs from adults in several ways. Children differ from adults in terms of their anatomy and body functioning. Their needs and requirements change as they go through the various stages of their early years of development especially in terms of their activities and interactions with caregivers and their immediate environment. Thus, having a framework that accounts for these differences is helpful in getting in-depth understanding of disability in children. Furthermore, since ICF-CY is based on ICF, it also helps in applying ICF to children when they become adults (Figure 1). This helps in continuity of care based on the type of disability they have. The framework is applicable to children up to 17 years of age.<sup>36</sup> It comprises both functioning and contextual factors. *Functioning* relates to anatomical structures and functioning of body and activities, and participation at individual level and at the level of the society. The *contextual factors* include environmental factors (immediate to more general environment of the disabled individual) and personal factors (age, gender, race, education, occupation, social background, etc). It is important to note that personal factors are not classified in ICF, they are crucial to consider as they influence various outcomes. It is the interplay and interaction of these factors that determine the extent of disability in an individual.<sup>35,36</sup>

### UNICEF/WG Module on Child functioning

The Multiple Indicator Cluster Survey (MICS) administered by UNICEF introduced a disability module for children in 2000 and collected data in 50 surveys from various LMICs. However, in 2011 UNICEF collaborated with the Washington Group (WG) to revise and develop a disability tool for assessing child functioning.<sup>46</sup> The tool is based on ICF-CY framework with focus on functioning. With the shift in focus

<sup>45</sup> ICF.

[http://apps.who.int/iris/bitstream/handle/10665/43737/9789241547321\\_eng.pdf;jsessionid=89EAA4247F5BCE885D389A9C177A5E20?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/43737/9789241547321_eng.pdf;jsessionid=89EAA4247F5BCE885D389A9C177A5E20?sequence=1)

<sup>46</sup> Loeb M, Cappa C, Cialesi R, de Palma E. Measuring child functioning: the Unicef/ Washington Group Module. *Salud Publica Mex.* 2017;59(4):485-7.



from impairment to functioning, the tool allows to early identify at-risk children for interventions. The tool covers the domains of seeing, hearing, walking, communication, learning, relationships, and playing. In addition, the domains of emotion, behavior, concentration and coping with change were also added to get a better understanding of child development and functioning. The questions were developed based on the previous work that the WG has done to assess disability data in adults.<sup>47</sup> Another important decision taken by the WG was to assess disability in children between 2-17 years of age; that is pre-school going children (2-4 years) and school-going children (5-17 years). Children under 2 years of age are not included due to the challenge associated with assessing development delays in such young children. In addition, cultural norms tend to vary and can influence child's developmental milestones during infancy.<sup>37, 48</sup>

The field testing for the tool was conducted in two rounds in several different settings including India, Belize, Oman, Montenegro, and the USA resulting in development of a final version of the tool that will be used for this study.<sup>49</sup>

The greatest advantage of this tool is that it does not need clinicians to administer it, this is easily done by survey enumerators.<sup>39,50</sup> The tool for 5-17-year-old children was validated in school settings in Fiji in 2015. The objective of the study was to determine if the UNICEF/Washington Group tool can be used by teachers to identify children at risk of disability for timely referral for further assessment and interventions.<sup>51,52</sup> A recent study from South Africa has used the tool for 2-4 years old children in its 2011 General Household Survey and National Census to generate epidemiological evidence on child disability and to identify types and extent of disabilities in children of this age group.<sup>43</sup> The same tool has been validated for implementation within community-settings in Uganda and other similar contexts.<sup>53</sup> In addition, UNICEF has implemented the tool in residential care setting in Ghana as part of their larger work on children in alternate care.<sup>54</sup>

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<sup>47</sup> WG. Washington Group on Disability Statistics Hyattsville, MD, USA: National Center for Health Statistics; 2017 [Available from: <http://www.washingtongroup-disability.com/>

<sup>48</sup> WG. Child Functioning Washington DC: The Washington Group on Disability Statistics; 2017 Available from: <http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability>

<sup>49</sup> Massey M, Chepp V, Zablotsky B, Creamer C. Analysis of cognitive interview testing of child disability questions in five countries Hyattsville, MD: National Center for Health Statistics; 2014

<sup>50</sup> Visser M, Nel M, Bronkhorst C, Brown L, Ezendam Z, Mackenzie K, et al. Childhood disability population-based surveillance: Assessment of the Ages and Stages Questionnaire Third Edition and Washington Group on Disability Statistics/UNICEF module on child functioning in a rural setting in South Africa. *Afr J Disabil.* 2016;5(1):265.

<sup>51</sup> Sprunt B, Hoq M, Sharma U, Marella M. Validating the UNICEF/Washington Group Child Functioning Module for Fijian schools to identify seeing, hearing, and walking difficulties. *Disabil Rehabil.* 2019;41(2):201-11

<sup>52</sup> Sprunt B, McPake B, Marella M. The UNICEF/Washington Group Child Functioning Module-Accuracy, Inter-Rater Reliability and Cut-Off Level for Disability Disaggregation of Fiji's Education Management Information System. *Int J Environ Res Public Health.* 2019;16(5).

<sup>53</sup> Zia N, Loeb M, Kajungu D, Galiwango E, Diener-West M, Wegener S, et al. Adaptation and validation of UNICEF/Washington group child functioning module at the Iganga-Mayuge health and demographic surveillance site in Uganda. *BMC Public Health.* 2020;20(1):1334.

<sup>54</sup> UNICEF. <https://www.unicef.org/protection/children-in-alternative-care>

## GOALS AND OBJECTIVES

This study was being conducted as part of Changing the Way We Care (CTWWC), a global initiative on care reform, including in Kenya. The initiative seeks to influence key stakeholders – including governments, families of children living in residential care, and donors - to provide, safe, and nurturing family care for children and pathways for children in residential care to return to their families and communities. The purpose of this study was to plan and implement a pilot project to undertake the measurement of disability amongst children in residential care and to support the dissemination and use of findings in Kenya.

For CTWWC, the goals were three-folds.

- Be part of a global discussion on how to measure prevalence of disability amongst children, including children in care
- Fulfil its commitment to disaggregate our results by disability status and learn about a vulnerable group of children
- Equip case managers with knowledge and tools to identify children’s needs to help begin the process of addressing them

To achieve these goals, following research questions were developed to guide the study methodology and their implementation.

- How many children within residential care facilities (with which CTWWC is working) in Kenya have disabilities? What is the type and degree of these disabilities?
- What sort of support would these children need? What is the local understanding of the availability of appropriate community-based support for families?
- What are the available measurement approaches for understanding the prevalence of children with disabilities? How can these be utilized with children living in residential care? How can measurement tools be linked to case management processes to guide support to children and their families?

## METHODS

### Study setting

This study was conducted in 18 residential care facilities in Nyamira, Kisumu, and Kilifi counties where CTWWC works in collaboration with the local implementing partners. The CTWWC team in Kenya comprises of national and county staff. In each county there is a case worker employed by a local partner non-governmental organization (NGO) or community-based organization (CBO) (1 each in Kisumu and Nyamira, and 2 in Kilifi) who work alongside multiple CCIs and their staff, some of whom are case workers. There are on average 2-3 staff at the selected residential facilities. These facility staff have received training in case management from CTWWC teams. In addition, the local team works closely with additional residential facilities in their respective counties.

### Study design and population

This was a **mixed methods study** comprising of a qualitative and quantitative phase. While the population of interest was children in residential care in Kenya, the respondents were key stakeholders involved in residential care policy development and service provision.

#### Qualitative phase

During the qualitative phase, interviews with residential care actors were conducted. Key informant interviews were conducted with **government officials and representatives of organizations of people with disabilities** to engage and learn more on local work around measurement of disability among children and potential gaps to address the needs of these children. These interviews focused on understanding the needs at the national and sub-national level to support children with disabilities living in residential care, facilitators and barriers in providing support to residential facilities (eg policies, leadership, resources allocation, training, workforce, infrastructure) to care for children with disabilities, current level of community-based support for family-based care children with disabilities, facilitators and barriers in providing non-residential community-based services and cohesive efforts towards needs of children with disabilities in residential care facilities and those returning to families.

In addition, in-depth interviews were conducted with **case managers/case workers/psychologists, managers of residential facilities, and primary caregivers of children** (in residential care). For this study, primary caregiver was defined to be person who spends the most time with the child and knows the most about the child. For CTWWC residential care facilities, the CTWWC staff was also interviewed. The focus of interviews with case managers, managers of residential facilities, and primary caregivers of children was to get an insight into experiences and challenges faced, support and needs of children with disabilities in residential care, availability of resources and support to address needs of children with disability in residential care, and perceived acceptability/feasibility and utilization of disability assessment tools as part of case management system for decision-making related to referral and need for intervention. Interviews with case managers/case workers and managers of residential facilities were also be conducted after implementing the Child Functioning Module (CFM) (see details below). Interviews after CFM implementation gauged experience, challenges, and utilization of the data gathered from the CFM and how it guided any changes in processes related to referral and intervention needed by children identified to have disability.

#### Quantitative phase

The quantitative study involved implementing the CFM using cross-sectional study design. CFM is an easy-to-use standardized disability assessment tool used for children between the ages of 2-17 years. As

explained in the opening section, the CFM was developed by the UNICEF/Washington Group on Disability Statistics.<sup>38</sup> It focuses on basic everyday activities and has expanded set of questions to assess functioning of a child. It can be administered at national level and can draw comparisons across time and countries. The tool is administered to the caregiver of a child, mostly mothers.

The tool has two versions, one for children between 2 years to 4 years of age with a total of 16 questions, and second for children between 5-17 years of age with 24 questions. There are eight domains covered in 2-4 years version including vision, hearing, mobility, fine motor, communication, learning, playing and controlling behavior. While 13 domains are covered in 5-17 years version. These include vision, hearing, mobility, self-care, communication, learning, remembering, concentration, accepting change, controlling behavior, making friends, anxiety and depression. Responses to most of the questions in both versions are recorded on 4-level Likert scale (0= no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all). However, there are some exceptions. The response option for controlling behavior for 2-4 year olds is 0=not at all, 1=the same or less, 2=more, and 3=a lot more. The response options for anxiety and depression questions for version for 5-17 year old is 0=daily, 1=weekly, 2=monthly, 3=a few times a year, 4=never. Each tool was translated into Swahili.

In addition to CFM data, basic demographic data was also collected. Most of this information was available as part of the regular documentation processes already implemented in the residential facilities in Kenya. For children identified to have disability based on the CFM data, additional information on child disability (type, cause, duration, use of assistive devices), well-being, and health seeking practices was also collected. The respondent for this phase was the primary caregiver of children. As mentioned above, primary caregiver was defined to be person who spends the most time with the child and knows the most about the child.

In the CTWWC residential care facilities, data was collected by case managers through review of child records and through discussions with child’s primary caregiver in the residential care (usually called house parent). There were some instances when a child is taken care of by more than one caregiver. In these instances, data was collected from all the relevant caregivers.

## Sample size

### Qualitative phase

A total of 20 key informant interviews were conducted with governmental officials, OPDs, protection services in Kenya. A list of affiliative organizations of key informants in Kenya is provided below in table 1.

**Table 1: List of organizations of key informants**

National Council of Children Services (NCCS)
Department of Children’s Services (DCS) – national, county and sub-county
Stahili Foundation
UNICEF
Special Olympics
Alternative Care Committee member within sub-county or county Area Advisory Councils
Ministry of Health at county level
Kilifi Disability Network
Education Assessment Resource Centers (EARCs)

Association for the Physically Disabled of Kenya (APDK) Kisumu
Child Protection Volunteers
Society for Persons with Disabilities Nyamira
National Council for Persons with Disabilities Nyamira
Gender & Social Services

In addition, 18 in-depth interviews were conducted with CTWWC and partner staff and CCI staff before the implementation of CFM. Of these 18, 10 interviewees from CCI staff also participated in a post-CFM implementation interview.

### Quantitative phase

Based on the available information, there were 471 children residing in the participating residential care facilities in Kenya.

### Stakeholder orientation workshops

Members of the Johns Hopkins International Injury Research Unit (JH-IIRU) and CTWWC conducted workshops in May and July 2022. The aim of the workshops was to orient the CTWWC program officers and local implementing partners to:

- Discuss disability and its conceptualization
- Understand challenges in measuring disability
- Introduce disability measurement tools
- Provide an overview of the project, its aims, approach, and timeline
- Discuss roles and responsibilities of team members

The workshops also facilitated review of the CFM tool and provided an opportunity to get direct feedback on data collection tool from the participants. In addition to CFM, supplemental questions in the data collection tool were grouped into several sections which included residential facility information, respondent information, child demographic information, child school history, child disability, history, child caregiving related information, and child healthcare access. Revisions were made to the tool before implementation, mostly to the supplemental questions on the child's background and disability, the CFM itself remained largely unchanged (see annex 1)

### Data collection and management

#### Qualitative phase

The data collection for key informant interviews and in-depth interviews was conducted by the JHU consultant. These interviews were conducted either in-person or virtually via Zoom or on phone depending upon availability of the key informant and where they are located. Purposive sampling was used during recruitment of the key informants with extensive input from the CTWWC team based in Kenya. The sampling approach allowed for exploration of the wide range of experiences of the stakeholders responsible to support children in residential care with focus on needs and support for children with disabilities.

Semi-structured interview guides were developed for various stakeholders. Questions in the guide covered three main areas: (a) support and needs of children with disabilities in residential care; (b)

utilization of disability assessment tools as part of case management system; (c) availability of resources and support to address needs of children with disability in residential care.

The key informant interviews took approximately 40-60 minutes and were conducted in English. However, to be more inclusive, with support from the local consultant, provision was kept for conducting the interviews in Kiswahili if any participant is not able to communicate fluently in English. All interviews were digitally recorded and transcribed upon receiving permission from the key informants. Permission for recording and transcription was sought as part of the oral consent. All digital audio files are stored on password-protected computers/laptops with access only to the study team. The digital audio files on the recorder were deleted once the files were copied onto the computers/laptops. No personal identifiers were collected during the interviews. However, interviewees were asked about their level of education, number of years of their affiliation with their current organization and years working with children in residential facilities.

### Quantitative phase

The data collection was conducted with support from CTWWC staff and partners working with residential facilities for children in the participating facilities. The staff and partners support the use of a case management toolkit. The toolkit is designed to support case planning for children in residential care and to explore possibility for reintegration with family members, and if safe to do so, to support this transition process. The toolkit has been adopted at the national level and is endorsed by the Government of Kenya. Training of social welfare workers in the use of the toolkit has been conducted by CTWWC in the selected counties where CTWWC operates. Data collection was undertaken by CCI staff who had been trained in the case management toolkit. With the use of the CFM within the data collection tool, the aim was to build their understanding of the disability data and its use to address needs of children with disabilities in the residential care within the case management process.

The case management toolkit is implemented in paper format. Since one of the aims is to integrate CFM into the current system, provision was kept collecting CFM data using paper format or for a paper print out to be included within the case management records. The collected data was entered directly or after use of the paper tool via an online platform that was developed and pre-tested based on available local resources at the selected facilities for this study. Data forms were available in English and Kiswahili. Translations were undertaken by experts on the team and thoroughly checked and refined. Questions were developed in Microsoft Excel .xls format and uploaded to KoBoToolbox (<https://www.kobotoolbox.org/>) for data collection. Questions had check box and free text entry formats to enter responses. Where appropriate, questions were designed to allow skip patterns. Mandatory fields were marked to address issues related to missing data. This exercise may support the facilities to make digital transition in future.

The Kobo app was downloaded to smart phones to allow for data collection using a user-specific password. These forms were accessible without internet or Wi-Fi connection to fill them. Once a form was filled, it could be saved on the tablet and submitted to a secure cloud server once internet and Wi-Fi connection becomes available. The electronic forms were submitted to a secure, encrypted cloud server, with no copy available on the tablet after submission to the cloud server. The server was only accessible to authorized study team members of CTWWC team and JHSPH. This ensured data confidentiality and security. Data was downloaded periodically from the server in MS Excel.

## Data analysis

### Qualitative phase

The data collection and analysis were conducted simultaneously, and interview questions were modified within the scope of this study through an iterative process to ensure the collection of rich information from the interviewees. All digital recordings were transcribed verbatim. Emerging themes were identified through reading of the transcripts, reflections, and field notes. Quotes for each theme were identified to support development of the narrative.

### Quantitative phase

The data analysis was conducted to determine prevalence of functional limitation in children in the residential care facilities and assess associated factors in these children. Functional limitation was categorized into the following categories (table 2). These cut-offs have been previously used in a study conducted in Uganda<sup>55</sup>. These categories are different from what are recommended by UNICEF/WG<sup>56</sup>. They recommend using binary categories where “no difficulty” and “some difficulty” is merged to form “No functional difficulty” category, and “a lot of difficulty” and “cannot do at all” is merged to form “With functional difficulty” category. While there is value in this binary categorization, the aim of integrating CFM into case management tool is to early identify children with these difficulties and refer them in a timely manner to allow diagnostic assessment and initiation of management. Combining the responses into a binary category tends to underestimate the prevalence of disability, and its severity. Therefore, based on the previous work done in Uganda<sup>52</sup>, four categories were defined to allow for those in “mild” category to be identified and referred for timely intervention.

**Table 2: Definition of categories of functional limitation**

Categories	Definition
None	“no difficulty” marked on all domains
Mild	“some difficulty” was the highest response for any one domain
Moderate	“a lot of difficulty” was the highest response for any one domain
Severe	“cannot do at all” was the highest response for any one domain

This approach is taken to prevent loss of information by using a binary yes/no response to categorize children with and without disability, respectively. The idea is to understand the extent of disability and report it along with various of functioning domains for example seeing, hearing, walking. Descriptive analysis was conducted to calculate the percentage of overall and domain-specific disability for different age groups and by county.

### Ethical approval

Ethical review and approval for this study will be sought from the Institutional Review Boards of the Johns Hopkins School of Public Health. In Kenya, local ethical approval was obtained from the Maseno

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<sup>55</sup> Zia N, Bachani AM, Kajungu D, Galiwango E, Loeb M, Diener-West M, Wegener S, Pariyo G, Hyder AA. Understanding child disability: Factors associated with child disability at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda. *PLoS One*. 2022 Apr 15;17(4):e0267182. doi: 10.1371/journal.pone.0267182. PMID: 35427403; PMCID: PMC9012358.

<sup>56</sup> UNICEF. <https://data.unicef.org/resources/module-child-functioning-tabulation-plan-narrative/>

University. In addition, research permit from National Commission for Science, Technology & Innovation (NACOSTI) was also obtained.



## RESULTS AND DISCUSSION

The results section is organized in two main sub-sections. The first, (insights from key informant interviews) presents results from key informant and in-depth interviews with focus on experiences of the interviewees in working in residential care facilities with children with disabilities. The second (CFM implementation) shares findings related to implementation of CFM. It starts with current practices in managing children with disabilities, implementation of CFM, and the experience of the facility staff in CFM. Under qualitative results, a summary is provided for each theme followed by details as synthesized from the key informant and stakeholder interviews. Please note that all the information provided by the interviewees is their own option and is not representative of the CCIs in Kenya.

### Insights from key informant interviews

The data collected from interviews provided an understanding of what support is needed by the stakeholders to address needs of children with disabilities in residential care and how those needs might be addressed with the care system in Kenya. It also gave insight into how various stakeholders engage with each other to coordinate needs of children with disabilities in residential care. This information generates evidence to formulate specific recommendations for future policies to enhance understanding of the needs of children with disabilities in Kenya.

A total of 20 key informant interviews were conducted. The distribution of males and females was equal. The majority had completed their educational up to master level. On average, the key informants have been working with children in residential care facilities for about 12.5 years (range: 2 to 32 years). A narrative of the key themes emerging from these interviews is presented below. A representative quote in italic is added for each key theme.

#### a. Current policy environment

*Summary:* The current policy environment has made it a priority to support children in need of care through development of various policies. While these policies look good on paper, the stakeholders shared that there are implementation gaps which preclude their full implementation and hence, have called for development of implementation processes relevant to Kenyan context.

Overall, providing care for children in alternative care settings is a **policy priority**. There are policies in place that govern alternative settings for children, for example the National Care Reform Strategy, Children's Act. In addition, there are several options for alternative care including foster families, adoption, community-based care, kinship care, Kafaalah (an Islamic practice of kinship care), and residential care. However, several stakeholders stressed that residential care settings should be seen as **temporary, not permanent, solutions**. Reintegrating children into families is a very high priority objective, and all stakeholders asserted that Kenya should do away with institutions in the near future (e.g., within ten years).

Several key informants shared that while there are policies in place, there is **room for improvement in the current alternative care policies**. For example, there is a need for a national plan of action to improve care for children. They were also of the opinion that within the current policy environment, collective support from donors and the government towards families at risk of separation would be beneficial; this could help reduce poverty levels through implementation of support programs (e.g., cash transfer program) and **raise awareness** of the available support for these families. In addition, it was noted that while policies may exist, there is lack of awareness about these policies among policymakers,

relevant stakeholders, and general population. When it comes to implementation of these policies, the on-ground implementation may not always align with the policies. Thus, there is a **need of implementation processes and guidelines** that support good practice and monitoring of these policies as well as their review.

A stakeholder very comprehensively noted, *“service delivery shortfalls exist, including lack of services, families lacking information about where to seek services, high costs of services, and stigma affecting care-seeking”*, indicating that raising awareness of policies would also be helpful for facilitating implementation.

#### **b. Facilitators and challenges to support children with disabilities**

*Summary:* Key informants identified various facilitators and barriers to support children with disabilities. These included factors associated at the policy level, residential care facility level, and family and community level. While each of these levels demand an in-depth assessment, the mention of these factors by the key informants is an acknowledgement that support to the children in residential care facilities in general and to children with disabilities specifically requires multisectoral collaborations and interventions that influence each of the mentioned levels.

Certain **facilitators** can help ensure that children are well cared for. A **strong family unit** (e.g., parents, caregivers, extended family members) helps establish a foundation for love and belonging. A supportive **societal environment**, including supportive laws, policies, and guidelines, extends this foundation. **Collaboration** between donors, civil society organizations, nongovernmental organizations, and government entities can help facilitate such an environment, for example through legislation or economic empowerment by way of loans, grants, and educational programs; ensuring supply of assistive devices for children with disabilities when and where they are needed; supporting strong maternal-child health care to ensure children are taken care of from the beginning.

Despite these facilitators, **challenges** to ensuring adequate care for children remain, particularly within residential care facilities. The biggest challenge within residential care is having **adequate resources** to meet the basic needs of the children and the unique needs that children with disabilities require. Resources include financial resources, physical facilities, and human resources (e.g., lack of volume and/or skilled staff to care for children).

At the family level, **familial factors** contribute to the needs of children with disabilities. Parental neglect and violence (including physical, sexual, and emotional) can permanently impact the way any child connects with others and forms relationships, particularly with caregivers such as those in alternative care facilities. Ignorance from families and communities can also lead to other negative downstream consequences, such as lack of school attendance. Often, low family incomes, especially given the rising costs of living, play a role in children’s development. As a result of their circumstances, each child has a unique background and set of needs, and support must be tailored to each individual situation. Children with disabilities face additional challenges, notably stigma and discrimination, which *“are some of the largest barriers to high quality care for children with disabilities; a lack of acceptance and denial of disability conditions by parents as a result of stigma leads to more stigma within the community, fueling an endless cycle of discrimination”*.

#### **c. Potential solutions**

*Summary:* Stakeholders identified solutions that could be implemented simultaneously at policy and community levels to strengthen the system for children with disabilities. These varied from sensitization of various government entities and communities to drawing upon learnings from another context. The key stakeholders also recognized the importance of have data to support implementation and monitoring of these solutions.

At the policy level, more can be done to promote the success of children with disabilities. Policies are in place, but implementation is the challenge. For instance, the National Council on Disability does not have enough power to **enforce policies at all levels**, with one stakeholder noting that *“the National Council on Disability offices are only at the county level but do not reach a more granular level; improving community-based rehabilitation services would increase access of high-quality services”*. There is a need to **sensitize departments** at all levels of government, including county and local, to disability issues so they know what is expected of them and what would be helpful, such as providing specific and measurable targets to meet. Kenya could benefit from **lessons learned in other countries** as it continues strengthening policies that support children with disabilities.

To do so, **disability-specific data on children with disabilities** in Kenya is needed. Counties do not have clear, concise data on children with disabilities, which limits their ability to monitor existing policies and develop new policies. From the data, Kenya could develop robust guidelines on identification, early treatment, and rehabilitation of children with disabilities. Improving identification practices for children with disabilities would help initiate early intervention, potentially minimizing disability severity in the future. A stakeholder shared that *“When you get to the county governments, and you need data to be able to intervene, there is no clear and concise data on children with disability... And that means that they are left out in terms of planning. They are left out in terms of resources, because there is no data. You cannot plan or allocate resources without data.”*

**Sensitizing the government and community** through increased awareness and de-stigmatization is crucial to improving care for children with disabilities. A key informant shared that *“one of the things that we are deliberately planning, is to be able to sensitize the various government departments within the networks on disability inclusion. So that even as they do their activities, or their plans, or they do their budgeting, they are able now to have that lens.”* Disability deserves the same amount of attention as other conditions, such as HIV, receive, and deliberate efforts to raise awareness should be made. *“Ministry of Health should also make steps to ensure that they go to the residential care institution to sensitize the workers within the residential care institution who are now to take care of this children”* This can be done through policy campaigns, media campaigns, and other forms of communication. Disabilities within families sometimes leads to familial breakdown; sometimes, women who give birth to children with disabilities are sent away. Part of the issue identified was that *“there is a lot of sensitization that needs to be done so that the caregivers, or the parents of these children becomes aware. Because you realize that most families do not know even some of the services that their disabled children can receive”*. Thus, it is critical that country-wide sensitization occurs at all levels en route to creating a more accepting, understanding environment for children with disabilities to thrive.

## Implementation of Child Functioning Module

The Child Functioning Module (CFM) was identified as a comprehensive resource to allow understanding of needs of children. The intent was to provide case managers with a resource for timely decision-making for early identification and referral of children in need of a detailed assessment and diagnosis of the cause of their functional limitation. It is an easy-to-use tool that could be implemented in residential

care settings and integrated into current case management protocols in Kenya. The CFM module was implemented in 18 facilities across the three counties. Prior to its implementation, the institution staff who were attending the training were asked about their experience with disability management. This was followed by training on using the CFM, and a post CFM implementation interview to gauge their experience of using the tool.

A total of 18 facility staff were interviewed before implementation of the CFM. Twelve of were females. Eight staff members had completed bachelors level education while six had received diploma. Only one member had a master's degree. On average, these staff members have been affiliated with the current residential care facility for about 7 years (range 9 months to 30 years).

## Pre-CFM implementation

### a. Children in residential care

*Summary:* In Kenya, children in residential care come from different social backgrounds and some from traumatic experiences. Their needs vary and case management plans for each child needs to be unique and customized. Addition of disability to the mix of vulnerabilities as children reintegrate can lead to stigma and discrimination, not only from their communities, but also their families. Case management plans need to account for any additional factors related to functioning and provide the support that children with disabilities and their families need.

Children in residential care can be **vulnerable** and require additional care and protection than those in families; however, the needs of each child will vary. Children in residential care come from all different backgrounds. **Reasons for entry into residential care** include poverty, lack of access to services, and familial neglect or child abuse, among many others and mainly combined reasons. Some children come from particularly traumatic backgrounds, as one stakeholder noted that they deal with *“broken children”*. There is a need to understand the specific circumstances and drivers beyond each child's entry into alternative care.

Children do not always receive the care they need in residential facilities, as one interviewee pointed out, *“there are some challenges you can meet, and maybe some other challenges where you cannot meet them”*. There is **no one-size-fits-all approach** for addressing the needs of children in residential care because needs and strengths vary dramatically between children. The stated end goal of most residential care facilities who participated in this study is for children to re-enter home and/or community life.

Within residential care facilities, **disability** is an issue, but most facilities are not suitable, properly accommodated, or capacitated for children with disabilities or functional limitations. Almost every CCI engaged in this research has reported working with children with disabilities within their facility, but they **report varied experiences**. Staff have managed children with both physical and cognitive disabilities. As one stakeholder noted, *“the challenge we have is... handling these children with disabilities within residential care, understanding their needs and raising their needs, and supporting their needs adequately”*. Some providers have had overall positive experiences, noting that *“children are lovable... they are people who bring joy around me... they have molded me as a person... they have special, special qualities”*. Other acknowledge the difficulties of working with children in residential care overall, asserting that *“we are also human beings... you can get emotional or psychologically affected by the condition or the situation you are in, and you can find yourself also being put down or being weighted down”*.

## b. Challenges of residential care facilities

*Summary:* The residential care facilities studied are limited in their capacity to provide care to the children despite the compassion felt by the facility staff towards children with disabilities. This is mainly due to limited human resources which is compounded by limited financial resources available to the facilities to function. This limits them in their ability to provide the necessary services to children with disabilities especially those with more complex needs.

Residential care facilities face numerous challenges when providing care to children. First, **staffing limitations** challenge residential care facilities' abilities to provide adequate care for their children. Staff need patience and a genuine passion to give children the dedication and attention they need. Facilities report being understaffed, which decreases the staff's bandwidth to attend to the children, and among the available staff, there is a shortage of trained, skilled workers. **High staff turnover** is disruptive; for instance, turnover complicates caregiver bonding. One stakeholder noted of her experience that "in the institution, you have to divide the love... I cannot pay attention to one child – I have to attend to these other ones".

**Financial constraints** are another major challenge residential care facilities face. Financial constraints result in insufficient funding for necessary resources and services. A lack of funding allocated to facilities means that not all needs can be addressed; instead, facilities are forced to prioritize the services that are essential to provide. One stakeholder commented that "*if something is beyond the budget that we have been given, we cannot do it, even if it is an emergency*". Residential care facilities are expected to provide education and medical care for children in addition to housing, but they have limited funds to accomplish these tasks. Auxiliary causes include facility maintenance, staff wages, and medical assessments. Though some government policies are in place to provide comprehensive health care, there is room for improvement in quantity and in implementation.

In terms of disability inclusiveness, facilities and facility staff are **not disability-accommodating**. Rather the facilities are sometimes, as one participant noted, "*like a dumping site for children with disability*". Addressing disability by way of enhancing facility capabilities is not a priority for most facilities. The physical infrastructure of facilities is not often accessible (e.g., a lack of ramps in buildings). Staff working in residential care facilities are not trained to support children with certain disabilities. For instance, communication barriers exist if staff are not appropriately trained (e.g., staff unable to communicate via sign language). Minor disabilities can sometimes be managed in residential care, but children with severe disabilities and advanced needs must be referred to facilities that are better equipped, with well-trained staff, to serve their needs.

## c. Improving care for children with disabilities

*Summary:* While work is being done to improve case management processes in Kenya, there is room for further improving the reunification/reintegration practices of residential care facilities and increasing their capacity by implementing rigorous and robust monitoring processes to deliver quality services and to transition those services to family care. Facility staff also recognized that the facilities are dependent on community partnerships and government level engagements to provide these services and cannot function on their own.

"Development is a right, not a privilege", and deliberate actions must be made to ensure **quality of care** for children in alternative care, including residential care facilities. Training for all staff, including

teachers, healthcare providers and support staff, is a crucial first step to ensuring that children and that all children will have access to reintegration services. There is a need for increased **awareness of child development, child functioning and disability-related issues within facilities**, training for basic skills like communication, and education on data collection that allows staff to measure their work with all children in their care (e.g., tracking how much progress children are making).

More concerted efforts to implement child development programs, disability identification processes and inclusive programs are needed. Addressing disability in the practices of residential care facilities should be a priority, especially for reintegration. **More robust monitoring and follow-up practices** would help facilities track the children's progress and the quality of care they are getting while at the facility and also when at home. Organizations like Changing the Way We Care have helped facilitate improvements in case management systems recent years, but there is room to further develop inclusive approaches through continuing and novel partnerships.

**Partnerships** are key to improving practices, and they allow facilities and families to access provide services they cannot provide on their own. *"We depend on community"*, noted one respondent, and networks between different government departments, organizations, and health care providers facilitate effective services within and connected to the residential care facility. Examples of such stakeholders include Ministry of Health, Department of Children's Services, Office for People with Disabilities, and social workers. Though these organizations can support children in many ways, one example provided by a respondent is that they may help connect children who would otherwise struggle to attend school to necessary support, like connecting children to in-house programs or enrolling them in specific schools for children with disabilities, which will aid their reunification.

#### **d. Experience working with functional limitations and child disability**

*Summary:* Facility staff indicated the need for developing capacity of the facility and its members to be able to work with and support children with functional limitations and disabilities. They indicated that in addition to having tools and resources for early identification and referrals, trainings and linkage to community-based efforts are needed to reduce stigma associated with disability.

While some staff report that prevalence of disability is low, others report that disability is a serious issue in their facility. In fact, following the training process, participants noted that they had many more children with disabilities in their care than they initially thought. Some facilities offer significant administrative support, but not all providers have had this experience. Providers would benefit from more comprehensive education and training on working with and supporting children with disabilities. Specifically, stakeholders called for **capacity building**, *"advanced training to know more about how to support and care for children with disabilities, and "sharing experience... to get some information on how to go about things"*.

Because not all disabilities are visible, **identification and referral of children with disabilities** can be challenging. There is a need to increase provider awareness of child development overall, and disability assessment tools; staff are aware of general categories of assessments, but not of **specific tools**. One provider noted that perhaps *"campaigns or trainings [would] equip people with knowledge so that we can easily identify people with disabilities"*, and early identification may lead to early intervention.

Lack of awareness surrounding disability leads to **stigmatization** within and beyond residential care facilities. Most providers understand disability as simply an inability to perform basic human functions, but the outside community, residential care facility staff, and other children in the facility harbor

**preconceived notions** surrounding disability. Education and lived experience can help with sensitization and changing mindsets. Sensitization is necessary on issues like *“care reform, alternative family care... things that can make [people] understand that okay, there are some small problems that may arise but... we can handle them within the family, or we can invite stakeholders who can come and talk to these children and help them”*.

### CFM implementation

The two version of the CFM tools were implemented in a total of 18 facilities across the three counties in Kenya. The breakdown of the number of children in the two age groups across the three counties is provided below. It shows that majority of children living in the residential care at the time of this study in participating facilities were between the ages of 5-17 years.

**Table 3: Number of children living in participating residential care facilities**

Counties	2-4 years	5-17 years
Kilifi	13	82
Kisumu	10	228
Nyamira	1	61
Total	24	371

#### a. Description of respondent (house parent) characteristics

Over 90% of the respondents for 2-4 years CFM version were between 26-50 years of age, around 79% were females. Around 50% had been educated to primary level. For this age group, the house parents had known the child for a few months. The shorter duration over which house parents have known the child corresponds to the smaller age bracket for these children and the time since their arrival at the residential care facility. For the CFM version for 5–17-year-olds, 88% of the house parents were between 26-50 years of age. Around 84% were females and 56% had secondary level education. The average duration of knowing the children varied but most house parents had known the child for a few years.

#### b. Description of child characteristics

Of the 24 children between the ages of 2-4 years, 57% were males. Over half of them were in school (n=13, 54%). All 13 children attended a formal school, while 38% were enrolled in onsite school. About 42% were in grade 2 and majority (62%) walked to school. Ten children never went to school as they were too young to attend. There was only one child who had dropped out of school due to financial reasons. The small sample of children between 2-4 years reflects the overall distribution of children in the selected residential care facilities participating in CTWWC<sup>57</sup>.

Of the 371 children between the ages of 5-17 years, 62% were males. Over 80% of them were in school. Around 77% attended a formal school and 49% were enrolled in onsite school. Majority were in primary or secondary classes. Around 40% walked to school. Of the 47 not in school, 33 were previously in school, but left due to financial reasons.

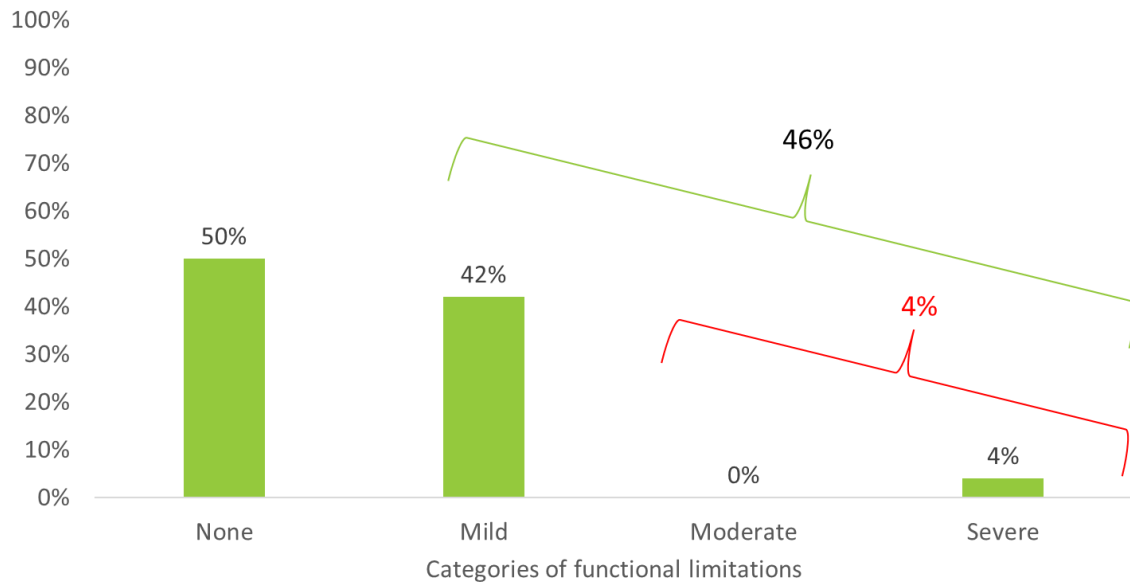
#### c. Prevalence of disability in residential care facilities

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<sup>57</sup> Situational Analysis Report for Children’s Institutions in Five Counties: Kiambu, Kilif i, Kisumu, Murang’a and Nyamira Summary Report. Available at <https://bettercarenetwork.org/library/the-continuum-of-care/residential-care/situational-analysis-report-for-childrens-institutions-in-five-counties-kiambu-kilif-i-kisumu-murang>.

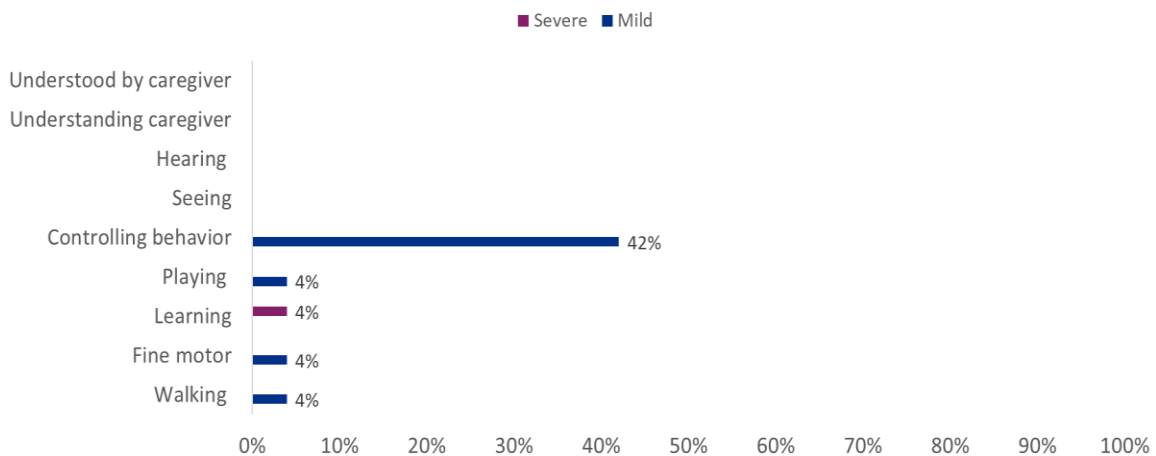
Among children between 2-4 years of age, 42% (n=11) had mild functional limitation, while 4% (n=1) had severe functional limitation (Figure 3).

**Figure 3: Distribution of categories of functional limitations among 2-4 years old children (n=24)**



No difficulty was reported for seeing, hearing, understanding by caregiver, being understood by caregiver. The majority of the children had mild difficulty in controlling behavior, playing, fine motor movements, and walking. Severe learning difficulty was reported for one child (Figure 4).

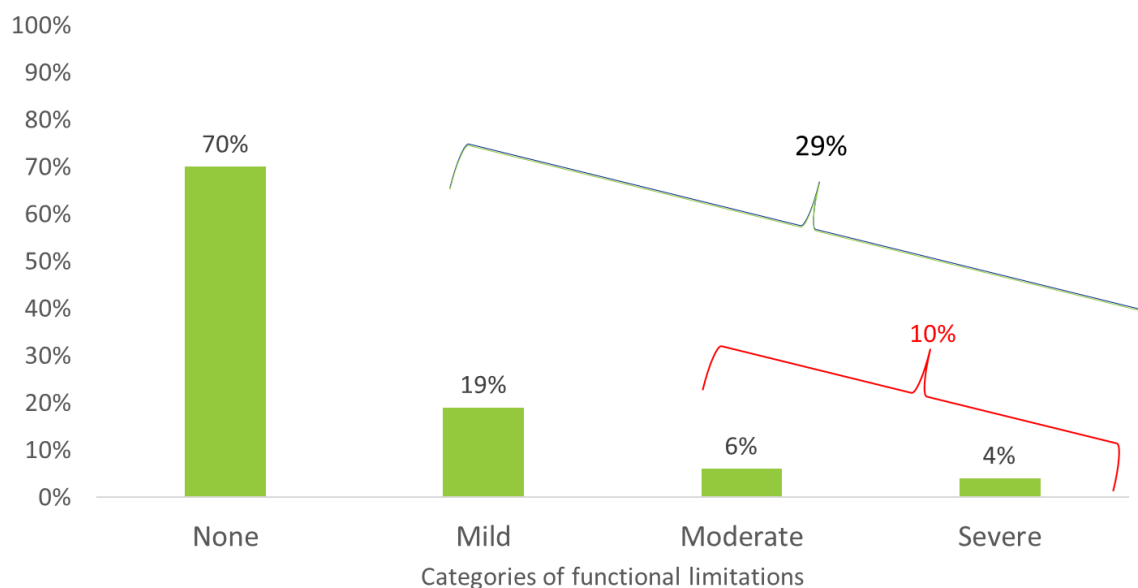
**Figure 4: Percentage of categories of functional limitations by domains among 2-4 years old children (n=24)**



Among children between 5-17 years of age, 19% had mild functional limitation, 6% had moderate functional limitation while 4% had severe functional limitation. This means that 10% of the children in residential care facilities in the three counties had moderate to severe functional limitation (Figure 5).



**Figure 5: Distribution of categories of functional limitations among 5-17 years old children (n=371)**



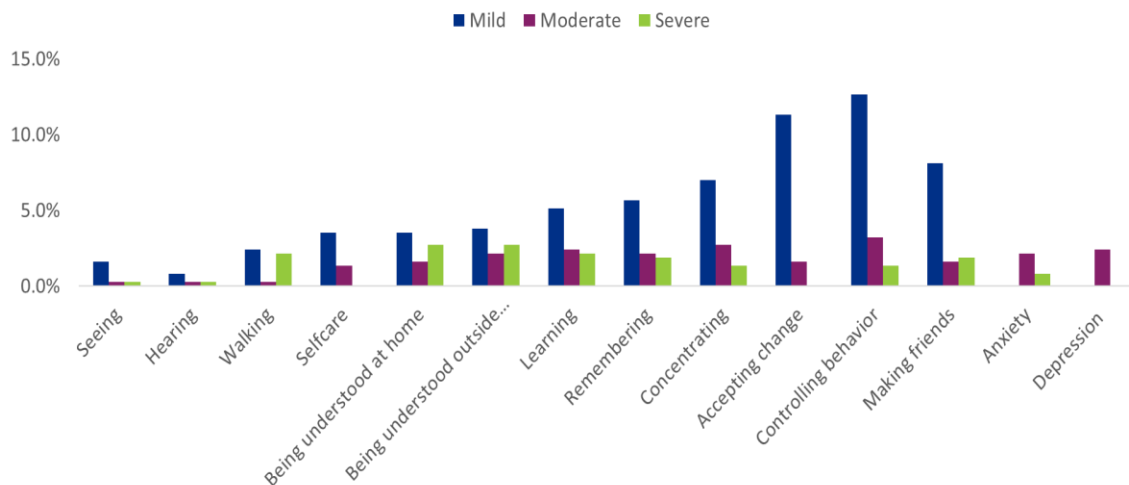
The majority of the children had functional limitation in the domains of learning, remembering, concentrating, accepting change, controlling behavior, and making friends (Figure 6).

As mentioned above, this study used four categories to define functional limitation instead of binary categories suggested by UNICEF/WG. This was done based on the concept of heterogeneity associated with disability measurement. The Likert scale responses in CFM therefore provide a more accurate picture of the spectrum of functional limitation across the various categories. People with different types of disability may face different types of barriers and limitations. Combining the various categories into one can mask impact of the limitations faced by children<sup>58</sup>. For example, interventions addressing functional limitations among children with severe disability will show the greatest impact in their outcome and functional status compared to those with mild or moderate functional limitation. However, it is equally critical to early identify mild cases of functional limitation, and make appropriate referral for timely intervention. This is to prevent these children from progressing to moderate and severe categories of functional limitation with any intervention and to provide them with inclusive opportunities to progress.

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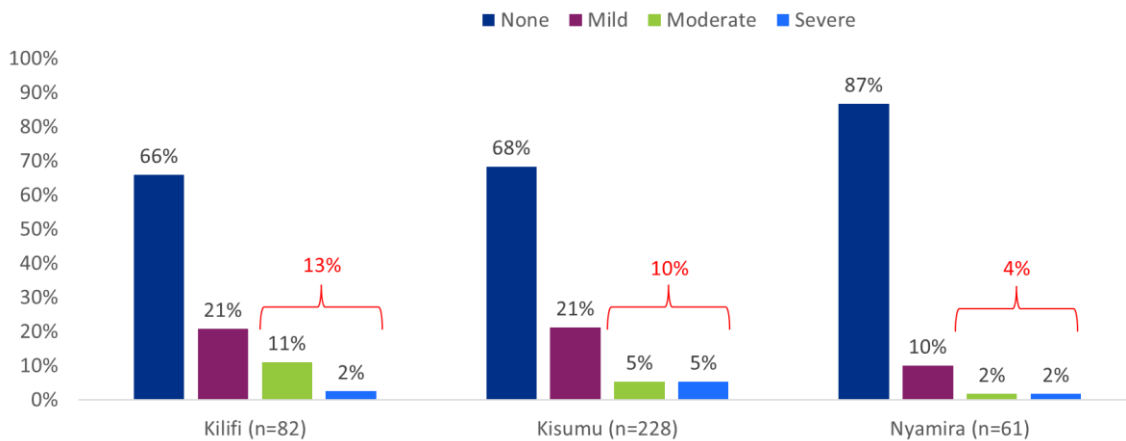
<sup>58</sup> Mont D. Measuring disability prevalence Washington DC: Disability and Development Team, HDNSP and The World Bank; 2007 [Available from: <http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf>.

**Figure 6: Percentage of categories of functional limitations by domains among 5-17 years old children (n=371)**



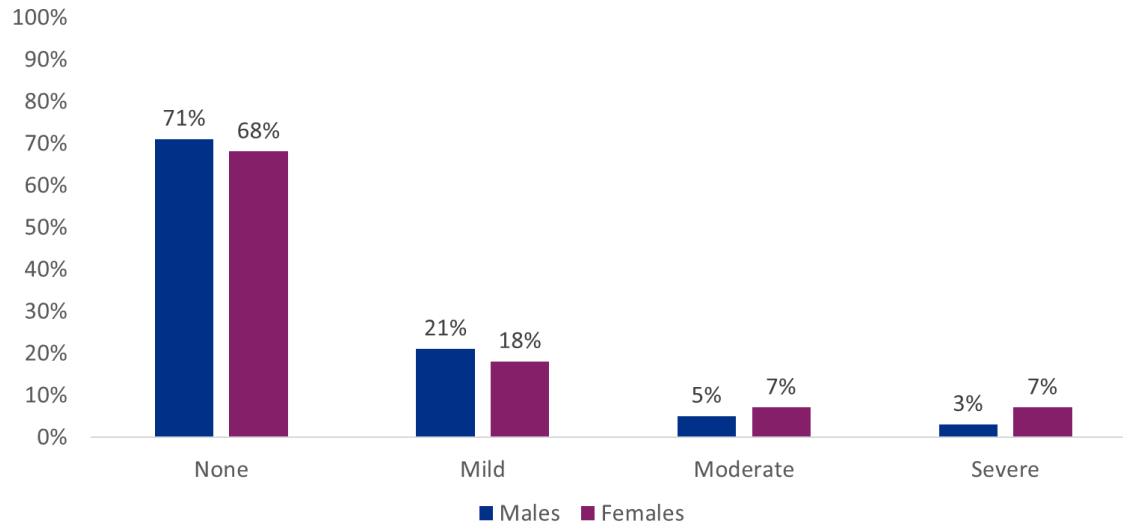
While most of the children between the ages of 5-17 years were in the residential care facilities in Kisumu, the prevalence of disability was highest in facilities in the Kilifi County (Figure 7).

**Figure 7: Percentage of categories of functional limitations by county for children 5-17 years old (n=371)**



Among children with moderate and severe functional limitation, the percentage of female children was higher compared to male children (Figure 8).

**Figure 8: Percentage of categories of functional limitations by gender for children 5-17 years old (n=371)**



About 11% (n=41) of the children were considered by their caregivers to have disability. Of these 41 children, 33 were assessed by a specialist to diagnose their disability.

**d. Caregiving needs of children with disabilities**

In addition to assessing level of functioning, caregiving needs of children was also assessed. This was done by asking caregivers if the child was considered to have disability. Several caregiving requirements of children were identified by the caregivers. About 27% had need for self-care (dressing, bathing, going to toilet etc), 11% needed support to move around, and 8% of the children needed help in eating. When caregivers were asked about their need to better care for the child, they indicated training of house parents/caregivers (69%), financial support (64%), educational material (58%), access to rehabilitation services (34%), access to healthcare services (30%), access to inclusive school (16%), and short break services for caregivers (3%).

**e. Access to health and rehabilitation care**

About 60% of the children whose caregivers considered them to have disability had medical care needs. These children were taken to hospital (66%), general medical practitioner (26%) either outside the facility or within the facility, or health center (6%). Twenty-nine percent of these children were taken for medical care via personal vehicle and 19% via public transportation. Among the 44 children whose caregivers knew about their disability, only 6 were told to have rehabilitation need. These included assistance from someone (50%), occupational therapy (50%), physical therapy (50%), mobility devices (33%), learning support (17%), vision glasses (17%), and speech therapy (17%). Of the 6 children told to have rehabilitation needs, 5 had received some form of rehabilitation within the residential facility.

## Post-CFM implementation

*Summary:* Overall, the facility staff found child functioning module (CFM) to be an easy tool to use, although there is a learning curve associated with its use as part of the case management processes. The benefits of the tool were noted not only at the facility level but beyond including at the community level to support reunification and longer-term reintegration of children into their families and communities.

The CFM tool **changed the perception of disability** from limitation to functionality as it frames questions about difficulties a child may have doing certain activities and moves away from inability, limitations and medical conditions. There were children with functional difficulties that had not been noticed prior to the administration of the tool. According to the facility staff, CFM can be used to “*bridge the data gap*” and support children with disabilities based on their functional limitation. This shift in perspectives from diagnosis to functionality creates a clearer link to support and assistive devices needed and interventions for children with disabilities. A staff member shared that “*Tool should be launched nationally to all CCI’s countrywide. It will give a blueprint of unidentified needs and how to bridge the gap [between identification and interventions]. Support children based on functionality. The tool should form part of the care plan and would inform how to handle children with difficulties in one area or another.*”

The CFM tool is user friendly with **simple, easy to understand** language and questions. While the staff had provision for using both the paper and online version of the tool, preference was given to the online version as data entry was easier and faster. However, there were instances where they didn’t have access to smart phones/ tablets/ computer making the process of data collection lengthy because the data entry had to be done at a cyber cafe at an additional cost. Tablet based data collection could be consider for future efforts to develop unified management information systems to harmonize data collection and data use processes for decision-making.

Although using the CFM tool is simple, there is a **learning curve** to using it. With practice the social workers found it easier to use. For example, the skipping pattern was confusing for some social workers at first, especially those who used paper versions of the tool. It took approximately 10-60 minutes to conduct one interview depending on whether there were any distractions. Also, getting the exact age of some of the children proved difficult as there are several abandoned children in residential institutions with no birth certificates. Although the full tool was available in Kiswahili, and responses options were translated into Dholuo and Ekegusii, it was noted that further **translation of the full CFM tool** to local languages is needed to ease its deployment.

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 through empowering of case workers and house parents who work very closely with children in the residential care facilities. It helped them to understand the needs of all children under their care including children who may be found to have certain functional difficulties and the interventions they need. 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 and support monitoring of their progress after receiving an intervention. CFM data would enable better planning as the child transitions from the institution to family-based care, thus highlighting its use beyond the residential care facilities.

## STRENGTHS AND LIMITATIONS

Addressing needs of children in residential care facilities is a priority in Kenya as the care system moves to ensure family care for all children. This study explored the feasibility of implementing the child functioning module in selected residential care facilities in Kenya. It allowed an opportunity to assess prevalence of functional limitations and disability among children living in these facilities. The tool could be implemented to gather information on child functioning irrespective of having a prior knowledge about disability. The study also developed capacity of the facility staff to objectively assess need of children with disabilities across a wide age range. The staff members did not need to have clinical background to conduct these assessments. As a mixed-methods study, findings are easily triangulated to provide holistic picture of the levels where interventions are needed to strength capacity of the facilities and its staff to support children with disabilities.

Having objective evidence through use of standard tools helps in developing, implementing, and monitoring interventions for children based on their needs. The evidence generated can also be used for advocacy to strengthen the facilities through provision of financial and non-financial resources. These resources could equip the residential care facilities to not only intervene as per child's need, but support sensitization efforts needed to raise awareness among communities and various stakeholder groups.

While the study has its strengths there are some limitations as well. This was a cross-sectional study that provide snapshot of the prevalence of disabilities among children in residential care. The study couldn't assess the utility of the CFM tool and how it helped the facility staff in making decisions related to referrals and monitoring of children identified to have functional limitation. Thus, it is important that longitudinal studies are conducted in future to understand the dynamic disability process and its impact on children. CFM assessed various domains comprising physical and developmental functioning. No clinical assessment was done to verify limitations reported by respondents. However, it is important that the CFM is implemented as a screening tool in residential care facilities to facilitate early identification and referral of children with disabilities so that they may receive the needed care in a timely manner.

## CONCLUSION AND WAY FORWARD

Alternative care for children is complex. Residential models of alternative care have particular struggles meeting the needs of all the children in their care, based on development, strengths and individual needs, which can include disabilities. In general, this study found that the facilities are not disability-friendly, staff lack necessary skills to understand and work with children with disabilities, and improving this is not a priority. Effort needs to be put into training the social service workforce, updating tools and methodologies for case management, and establishing referral networks. Residential care facilities also need to be better prepared to support children's families during reunification and reintegration. This starts with helping them to understanding the child's needs and strengths, any limitations and what services are available to the family locally and how to access them. Awareness raising and service capacity building, by way of improved tools, resources, and skills, will improve families' and communities' ability to care for their children and likely reduce stigma. These are services that residential care facilities could consider providing as they transition towards family care and away from residential models, as foreseen in the National Care Reform Strategy.

Given the implementation and endorsement of care reform at the national level in Kenya, this study provides an opportunity to engage with the government to ensure that children with disabilities are not left behind and that tools like the CFM are part of the case management toolkit. In addition, data driven decision-making is the key. Having robust and timely availability of the data on the children in care would support implementation and monitoring of relevant policies and interventions for reintegration. The government can play a key role by investing in data systems and key indicators for reintegration, which can be disaggregated to show if processes are disability inclusive.

Furthermore, close collaboration with the government and alternative care services, including residential care facilities, is needed to develop strategic plans for the facilities to provide details on agreed upon indicators for monitoring the implementation of the care reform across the country. Within the care reform agenda, more concerted efforts are needed to implement disability-inclusive programs. The evidence for which can be generated through collection of disability data about alternative care, including from residential care facilities, and as children move back into family care.

Beyond Kenya, this study provides comparable data that could be used across other contexts where CFM is being used in alternative care, an opportunity to contribute towards the global momentum on supporting better care for children, without leaving those with disabilities behind.

# ANNEXES

## Annex 1: Data collection tool

<b>Study ID [NOTE: to be assigned by the study team]:</b> _____		
<b>OVERALL INSTRUCTIONS:</b>		
<ul style="list-style-type: none"> <li>- This questionnaire will focus on children currently resident within a participating residential care facility. One questionnaire is to be filled separately for each child residing in the participating residential care facility.</li> <li>- The respondent must be the child’s primary caregiver/house parent. They should be the person who knows the child (2-17 years of age) the best. If it is difficult to identify one person then it is possible to have more than one respondent, however, please still identify one primary respondent per child – this is the person who should respond to the questions in the “respondent information” section (RI).</li> <li>- Do not mention the word ‘disability’ in the introduction, nor at any other time during the entire interview process.</li> <li>- Data recording:             <ul style="list-style-type: none"> <li>o Use a pencil for writing. It will be easier to erase any information from the questionnaire or rewrite words or sentences. The interviewer should not erase any notes made, as they can be useful. Red ink is not to be used as it is for editor’s corrections.</li> <li>o The information must be legible. Illegible handwriting is not of much use if only the interviewer can read it.</li> <li>o Check that all the questions have been asked. If a question has been skipped by mistake, it can be corrected. If the respondent decides to change her mind on one of the options, the new answer must then be recorded.</li> </ul> </li> </ul>		
<b>Interviewer name:</b> _____ <b>Date of Interview:</b> _____ <b>Residential facility ID:</b> _____		
<b>RESIDENTIAL FACILITY INFORMATION</b>		<b>RF</b>
<b>INSTRUCTIONS:</b> The following questions are about the residential facility where the child lives. COMPLETE ALL QUESTIONS IN THIS SECTION.		
<b>RF1.</b> Name of the residential facility		
<b>RF2.</b> County of the residential facility		
<b>RF3.</b> Subcounty of the residential facility		
<b>RESPONDENT INFORMATION</b>		<b>RI</b>
<b>INSTRUCTIONS:</b> The following questions are related to the basic information of the respondent – the main person to be providing information about the child. If other people are involved, please note this in RI4. COMPLETE ALL QUESTIONS IN THIS SECTION.		
<b>RI1.</b> How old are you?	1. Less than 18 years 2. 18 – 25 years 3. 26 – 50 years 4. More than 50 years	
<b>RI2.</b> What is the sex of the respondent? <i>NOTE: ask the question and then mark the response, no need to read the response options</i>	1. Male 2. Female 3. Intersex	
<b>RI3.</b> What is your education level?	1. No education 2. Some primary 3. Completed primary 4. Some secondary 5. Completed secondary	

	6. More than secondary	
<b>RI4.</b> How many other people are also providing information about the child?		
<b>INSTRUCTIONS:</b> The questions from here onwards are related to the child identified for this questionnaire.		
<b>CHILD DEMOGRAPHIC INFORMATION</b>		<b>CD</b>
<b>INSTRUCTIONS:</b> Following questions ask about basic information about the child. COMPLETE ALL QUESTIONS IN THIS SECTION.		
<b>CD1.</b> How long have you known the child <i>NOTE: Indicate days, weeks, months, or years, as appropriate</i>		
<b>CD2i.</b> What is the age of the child in years?	1. Two to four years 2. Five to 10 years 3. 11 to 14 years 4. 15 to 17 years	
<b>CD2ii.</b> Indicate how child's age is verified.	1. Could not verify 2. Birth certificate 3. Facility records 4. Other (Specify)  _____ _____ _____	
<b>CD3.</b> What is the sex of the child?	1. Male 2. Female 3. Intersex	
<b>CD4.</b> If known, what is the ethnic group of the child?		
<b>CHILD SCHOOL HISTORY</b>		<b>CSh</b>
<b>INSTRUCTIONS:</b> Following questions are about the child's education. <b>FOLLOW SKIP PATTERN FOR QUESTIONS CSH1.</b>		
<b>CSh1.</b> Is the child currently attending school?	1. Yes 2. No 98. Don't know	2ÀCSh5 98À CSh5
<b>CSh2.</b> What type of school is the child attending?	1. Formal 2. Nonformal	
<b>CSh3.</b> What class/grade is the child currently attending?	_____ 98. Don't know	
<b>CSh4.</b> How does the child get to school?	1. Onsite school 2. Private vehicle 3. Public transport 4. School van 5. Motorcycle (boda boda) 6. Walk 97. Other (specify) 98. Don't know	
<b>CSh5.</b> Was the child ever in school?	1. Yes, the child was previously in school 2. No, the child has never been in school 98. Don't know	



<b>CSH6.</b> What is the child’s reason for leaving or not going to school?	1. School not suitable for children with disabilities 2. School refused admission to the child 3. Financial difficulties of the family 4. Bullying by other children in school 5. Too young to be in school 97. Other (specify) 98. Don’t know	
<b>CHILD FUNCTIONING (AGE 2-4 YEARS)</b>		<b>CF</b>
<b>INSTRUCTIONS: THESE QUESTIONS ARE FOR CHILDREN 2-4 YEARS OF AGE ONLY.</b> Following questions ask the respondent (primary caregiver) about difficulties the child may have. In the following questions, you will be asked to answer by selecting one of four possible answer choices. For each question, would you say that the child has: 1) no difficulty 2) some difficulty (less than 50% of the time) 3) a lot of difficulty (more than 50% of the time) 4) cannot do at all. Repeat the categories during the individual questions whenever the respondent does not use an answer category. <b><u>FOLLOW SKIP PATTERN FOR QUESTIONS CF1 – CF10.</u></b>		
<b>CF1.</b> Does the child wear glasses or contact lenses?	1. Yes 2. No	1ÀCF2 2ÀCF3
<b>CF2.</b> When wearing his/her glasses or contact lenses, does the child have difficulty seeing? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot see at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1 À CF4 2 À CF4 3 À CF4 4 À CF4
<b>CF3.</b> Does the child have difficulty seeing without glasses? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot see at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
<b>CF4.</b> Does the child use a hearing aid?	1. Yes 2. No	1ÀCF5 2ÀCF6
<b>CF5.</b> When using his/her hearing aid, does the child have difficulty hearing sounds like peoples’ voices or music? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot hear at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1 À CF7 2 À CF7 3 À CF7 4 À CF7
<b>CF6.</b> Does the child have difficulty hearing sounds like peoples’ voices or music without a hearing aid? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot hear at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
<b>CF7a.</b> Does the child walk?	1. Yes 2. No	
<b>CF7b.</b> Does the child use any equipment or receive assistance for walking?	1. Yes 2. No	2ÀCF10
<b>CF8.</b> Without his/her equipment or assistance, does the child have difficulty walking?	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	

<p><i>Would you say the child has: some difficulty, a lot of difficulty or cannot walk at all?</i></p> <p><i>NOTE: The category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.</i></p>		
<p><b>CF9.</b> With his/her equipment or assistance, does the child have difficulty walking? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot walk at all?</i></p>	<p>1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all</p>	<p>1ÀCF11 2ÀCF11 3ÀCF11 4ÀCF11</p>
<p><b>CF10.</b> Compared with children of the same age, does the child have difficulty walking? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot walk at all?</i></p>	<p>1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all</p>	
<p><b>INSTRUCTIONS: COMPLETE ALL THE QUESTIONS FROM CF11 – CF16.</b></p>		
<p><b>CF11.</b> Compared with children of the same age, does the child have difficulty picking up small objects with his/her hand? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<p>1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all</p>	
<p><b>CF12.</b> Does the child have difficulty understanding you? Can the child follow simple directions? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<p>1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all</p>	
<p><b>CF13.</b> When the child speaks, do you have difficulty understanding him/her? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p> <p><i>NOTE: if not speaking, mark option 4. Indicate sign language, if applicable.</i></p>	<p>1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all</p>	
<p><b>CF14.</b> Compared with children of the same age, does the child have difficulty learning things? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p> <p><i>NOTE: Learning things could be learning to feed themselves, put clothes on, learning in pre-school</i></p>	<p>1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all</p>	
<p><b>CF15.</b> Compared with children of the same age, does the child have difficulty playing? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<p>1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all</p>	
<p>The next question has different options for answers. Read the options after each question.</p>		
<p><b>CF16.</b> Compared with children of the same age, how much does the child kick, bite or hit other children or adults? <i>Would you say the child does not do these things at all, does them the same or less than other children, does them more than other children or does them a lot more than other children?</i></p>	<p>1. Not at all 2. The same or less 3. More 4. A lot more</p>	<p><b>SKIP TO CDI1</b></p>
<p><b>CHILD FUNCTIONING (AGE 5-17)</b></p>		<p><b>CF</b></p>
<p><b>INSTRUCTIONS: THESE QUESTIONS ARE FOR CHILDREN 5-17 YEARS OF AGE ONLY.</b></p>		

Following questions ask the caregiver about difficulties the child may have. In the following questions, you will be asked to answer by selecting one of four possible answer choices. For each question, would you say that the child has:

- 1) no difficulty
- 2) some difficulty (less than 50% of the time)
- 3) a lot of difficulty (more than 50% of the time)
- 4) cannot do at all.

Repeat the categories during the individual questions whenever the respondent does not use an answer category.

**FOLLOW SKIP PATTERN FOR QUESTIONS CF1 – CF13.**

<b>CF1.</b> Does the child wear glasses or contact lenses?	1. Yes 2. No	1ÀCF2 2ÀCF3
<b>CF2.</b> When wearing his/her glasses or contact lenses, does the child have difficulty seeing? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot see at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1 À CF4 2 À CF4 3 À CF4 4 À CF4
<b>CF3.</b> Does the child have difficulty seeing without glasses? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot see at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
<b>CF4.</b> Does the child use a hearing aid?	1. Yes 2. No	1ÀCF5 2ÀCF6
<b>CF5.</b> When using his/her hearing aid, does the child have difficulty hearing sounds like peoples' voices or music? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot hear at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1 À CF7 2 À CF7 3 À CF7 4 À CF7
<b>CF6.</b> Does the child have difficulty hearing sounds like peoples' voices or music without a hearing aid? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot hear at all?</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
<b>CF7.</b> Does the child use any equipment or receive assistance for walking?	1. Yes 2. No	2ÀCF12
<b>CF8.</b> Without his/her equipment or assistance, does the child have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. <i>Would you say the child has: some difficulty, a lot of difficulty or cannot walk at all?</i>  <i>NOTE: The category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.</i>	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	3ÀCF10 4ÀCF10
<b>CF9.</b> Without his/her equipment or assistance, does the child have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football field. <i>Would you say the child has: some difficulty, a lot of difficulty or cannot walk at all?</i>  <i>NOTE: The category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.</i>	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	

<p><b>CF10.</b> With his/her equipment or assistance, does the child have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot walk at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	<p>3ACF14 4ACF14</p>
<p><b>CF11.</b> With his/her equipment or assistance, does the child have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot walk at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	<p>1ACF14 2ACF14 3ACF14 4ACF14</p>
<p><b>CF12.</b> Compared with children of the same age, does the child have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot walk at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	<p>3ACF14 4ACF14</p>
<p><b>CF13.</b> Compared with children of the same age, does the child have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot walk at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	
<p><b>INSTRUCTIONS:</b> COMPLETE ALL THE QUESTIONS FROM CF14 – CF24.</p>		
<p><b>CF14.</b> Does the child have difficulty with self-care such as feeding or dressing himself/herself? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	
<p><b>CF15.</b> When the child speaks, does he/she have difficulty being understood by people inside of this facility? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p> <p><i>NOTE: Inside means regular everyday contacts</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	
<p><b>CF16.</b> When the child speaks, does he/she have difficulty being understood by people outside of this facility? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p> <p><i>NOTE: Outside means not everyday contacts and interactions</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	
<p><b>CF17.</b> Compared with children of the same age, does the child have difficulty learning to do new things? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	
<p><b>CF18.</b> Compared with children of the same age, does the child have difficulty remembering things? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	
<p><b>CF19.</b> Does the child have difficulty concentrating on an activity that he/she enjoys doing? <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<ol style="list-style-type: none"> <li>1. No difficulty</li> <li>2. Some difficulty</li> <li>3. A lot of difficulty</li> <li>4. Cannot do at all</li> </ol>	

<p><b>CF20.</b> Does the child have difficulty accepting changes in his/her routine?  <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<p>1. No difficulty  2. Some difficulty  3. A lot of difficulty  4. Cannot do at all</p>	
<p><b>CF21.</b> Compared with children of the same age, does the child have difficulty controlling his/her behavior?  <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<p>1. No difficulty  2. Some difficulty  3. A lot of difficulty  4. Cannot do at all</p>	
<p><b>CF22.</b> Does the child have difficulty making friends?  <i>Would you say the child has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?</i></p>	<p>1. No difficulty  2. Some difficulty  3. A lot of difficulty  4. Cannot do at all</p>	
<p><b>INSTRUCTIONS:</b> The next questions have different options for answers. Read the options after each question.</p>		
<p><b>CF23.</b> How often does the child seem very anxious, nervous, or worried?  <i>Would you say: always, often, sometimes, rarely, or never?</i></p>	<p>1. Always  2. Often  3. Sometimes  4. Rarely  5. Never</p>	
<p><b>CF24.</b> How often does the child seem very sad or depressed?  <i>Would you say: always, often, sometimes, rarely, or never?</i></p>	<p>1. Always  2. Often  3. Sometimes  4. Rarely  5. Never</p>	
<p><b>CHILD DISABILITY HISTORY</b></p>		<p><b>CDI</b></p>
<p><b>INSTRUCTIONS:</b> Following questions ask about the cause and duration of any disability that is already being addressed.</p>		
<p><b>CDi1.</b> Do you consider this child to have a disability?</p>	<p>1. Yes  2. No</p>	
<p><b>CDi2.</b> Has the child been assessed by a specialist to indicate a disability?</p>	<p>1. Yes  2. No  98. Don't know</p>	<p>If either CDi1 or CDi2 are 1.  Yes→CDi3  If not→CLOSE</p>
<p><b>CDi3.</b> How long has the child had this disability?   <i>NOTE: specify day, weeks, months, years as appropriate</i></p>	<p>_____</p> <p>98. Don't know</p>	
<p><b>CHILD CAREGIVING RELATED INFORMATION</b></p>		<p><b>CC</b></p>
<p><b>INSTRUCTIONS: COMPLETE ALL QUESTIONS IN THIS SECTION.</b> Following questions ask about the caregiving needs of the child with disability.</p>		
<p><b>CC1.</b> What are the current specific caregiving requirements of the child?   <i>NOTE: Can mark more than one option</i></p>	<p>1. Needs help with eating  2. Needs help with self-care (eg. dressing, bathing, going to toilet etc)  3. Needs help to move around  4. None  97. Other (specify)  98. Don't know</p>	
<p><b>CC2.</b> How frequently does the child need specific caregiving?</p>	<p>1. All the time  2. Sometimes  3. Occasionally</p>	

	4. Not at all 97. Other (specify) 98. Don't know	
<b>CC3.</b> What do you need to better care for the child with the disability? <i>Can mark more than one option</i> <i>Or</i> What does the residential care facility need to best care for this child?	1. Education materials 2. Financial support 3. Access to inclusive school 4. Access to healthcare services 5. Access to rehabilitation services 6. Respite / short break services for caregivers 7. Training of house parents/caregivers 97. Other (specify) 98. Don't know	
<b>CHILD HEALTHCARE ACCESS</b>		<b>CH</b>
<b>INSTRUCTIONS: FOLLOW SKIP PATTERN TO COMPLETE QUESTIONS IN THIS SECTION.</b> Following questions ask about access to medical care and rehabilitation care for the child.		
<b>Medical care</b> includes any medical care that the child needed for their disability for example visit to the doctor, getting medicines for their disability.		
<b>Rehabilitation care</b> means any care received by the child to help cope with their disability for example physical therapy for making muscles strong.		
<b>CH1.</b> Does the child need medical care?  <i>NOTE: <b>Medical care</b> includes any medical care that the child needed for their disability for example visit to the doctor, getting medicines for their disability.</i>	1. Yes 2. No 98. Don't know	2 à CH9 98 à CH9
<b>CH2.</b> How frequently does the child need medical care?	1. All the time 2. Sometimes 3. Occasionally 4. Never 97. Other (specify) 98. Don't know	
<b>CH3.</b> What was the most recent reason for the child to receive medical care?	1. Injury 2. Seizure/s 3. Medicine refill 4. Illness 5. Immunization 6. Regular check-up 97. Other (specify) 98. Don't know	
<b>CH4.</b> Based on the most recent reason mentioned in CH3, where did the child receive medical care?	1. Hospital 2. Health clinic/center 3. General medical practitioner outside of facility 4. Community health worker 5. Traditional healer 6. Pharmacy 7. General medical practitioner within the facility	1 à CH5 2 à CH5 3 à CH5 4 à CH5 5 à CH5 6 à CH5 7 à CH9 8 à CH9

	8. Others within the facility 97. Other (specify) 98. Don't know	98 à CH9
<b>CH5.</b> If outside the facility, how do you usually get to where the child needs medical care?	1. Private vehicle 2. Public transport 3. Taxi 4. Motorcycle (Boda Boda) 5. Ambulance 6. Walk 97. Other (specify) 98. Don't know	
<b>CH6.</b> If outside the facility, what was the approximate distance (in kilometers) traveled to receive the child's most recent medical care?	_____	
<b>CH7.</b> If outside the facility, how long did it take to reach the facility for medical care last time?	1. Less than 1 hour 2. 1 - 2 hours 3. 3 – 6 hours 4. 7 – 9 hours 5. 10 – 12 hours 6. 13 – 24 hours 7. More than 24 hours 98. Don't know	
<b>CH8.</b> If outside the facility, what was the cost of transportation to the facility for medical care last time?  <i>NOTE: provide the amount in Kenya shillings</i>	_____ 98. Don't know	
<b>CH9.</b> Have you ever been told that the child needs rehabilitation care?  <i>NOTE: <b>Rehabilitation care</b> means any care received by the child to help cope with their disability, for example physical therapy for making muscles strong.</i>	1. Yes 2. No 98. Don't know	2àCH12 98àClose
<b>CH10.</b> What type of rehabilitation/correction is needed?	1. Mobility devices 2. Hearing aid 3. Vision glasses 4. Medication 5. Someone's assistance 6. Sign language 7. Surgical correction 8. Cognitive stimulation 9. Learning support 10. Occupational therapy 11. Physical therapy 12. Speech therapy 97. Other (specify) 98. Don't know	
<b>CH11.</b> Has the child ever received the rehabilitation needed?	1. Yes 2. No 98. Don't know	1àCH12 2àCH14 98àClose

<b>CH12.</b> Did the child receive the rehabilitation within the facility or outside the facility?	1. Within the facility 2. Outside the facility 98. Don't know	1àClose  98àClose
<b>CH13.</b> What is the total cost associated with the type of rehabilitation/correction that the child needed? (provide response in local currency)	_____ 98. Don't know	àClose
<b>CH14.</b> Why was the child not able to receive the rehabilitation needed?	1. Financial cost 2. Lack of transportation 3. Rehabilitation would not help the child 4. Not aware of where to access rehabilitation needed 5. Lack of trained rehabilitation staff 97. Other (specify) 98. Don't know	
<p>CLOSE: That's all the questions that I have. Thank you for responding to the questions related to this child. Do you have any final comments that it would be important to record?</p> <p><i>NOTE: Add additional comments here.</i></p> <hr/> <hr/> <hr/> <hr/> <hr/> <p>CLOSING NOTE: Ensure that all questions have been responded and no response is missing.</p>		