



# STUDY REPORT

3/18/2024

Situation of Children with Disability in Turkana  
West Sub County, Turkana County, Kenya



*Photos courtesy: Waldorf Kakuma Project*



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**TABLE OF CONTENTS**

TABLE OF CONTENTS .....	I
LIST OF FIGURES.....	III
LIST OF TABLES.....	IV
ACKNOWLEDGEMENTS .....	V
ACRONYMS AND ABBREVIATIONS.....	VI
EXECUTIVE SUMMARY .....	VII
1. INTRODUCTION.....	1
1.1 WALDORF KAKUMA PROJECT.....	1
1.2 STUDY PURPOSE AND OBJECTIVES.....	1
1.3 THE CONTEXT.....	2
2. STUDY SCOPE, APPROACH AND METHODOLOGY .....	6
2.1. SCOPE .....	6
2.2 SAMPLING PLAN.....	6
2.3 DATA COLLECTION AND SAMPLES REACHED.....	6
3. STUDY FINDINGS.....	8
3.1 ASSESSMENT OF CHILDREN WITH DISABILITY (CFM) .....	8
3.1.1 <i>Sight</i> .....	8
3.1.2 <i>Hearing</i> .....	9
3.1.3 <i>Walking</i> .....	10
3.1.4 <i>Picking up small objects with hands</i> .....	11
3.1.5 <i>Understanding the caregiver</i> .....	12
3.1.6 <i>Learning Abilities</i> .....	12
3.1.7 <i>Remembering Abilities</i> .....	13
3.1.8 <i>Concentration</i> .....	14
3.1.9 <i>Accepting change in routine</i> .....	14
3.1.10 <i>Controlling own behaviour</i> .....	15
3.1.11 <i>Making friends</i> .....	15
3.1.12 <i>Seeming very anxious, nervous, and worried</i> .....	15
3.1.13 <i>Seeming very sad and depressed</i> .....	16
3.1.14 <i>Playing</i> .....	16
3.1.15 <i>Kick, bite, or hit other children</i> .....	17
3.1.16 <i>Self-care such as feeding and dressing</i> .....	17
3.1.17 <i>Difficulty being understood inside the household</i> .....	17
3.1.18 <i>Albinism</i> .....	18
3.2 EDUCATION SITUATION OF CHILDREN WITH DISABILITIES .....	18
3.3 PROVISION OF HEALTH SERVICES FOR CHILDREN WITH DISABILITY .....	27
3.3.1 <i>Health providers</i> .....	29
3.3.2 <i>Physical access to health services</i> .....	29
3.4 COLLABORATIVE PSYCHOSOCIAL AND SAFETY SUPPORT SYSTEMS FOR CHILDREN WITH DISABILITIES .....	32
3.4.1 <i>Available services</i> .....	32
3.4.2 <i>Membership in parental support groups</i> .....	33
3.4.3 <i>Availability of play materials</i> .....	35
3.5 REGISTRATION OF CHILDREN AND COMMUNITY SUPPORT SYSTEMS.....	38
3.6 KNOWLEDGE ATTITUDES AND PERCEPTIONS ON DISABILITY AND CHILDREN WITH DISABILITY .....	39
3.6.1 <i>Knowledge of and attitudes towards types of disability</i> .....	39
3.6.2 <i>Practices towards Children with disability</i> .....	41
3.6.3 <i>Rights of children with disability</i> .....	44
3.6.4 <i>Comfort and Knowledge of caring children with disability</i> .....	45

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3.7. BIRTH REGISTRATION, AND VACCINATION COVERAGE .....	47
3.7.1 <i>Where the child was born</i> .....	47
3.7.2 <i>Birth notifications</i> .....	48
3.7.3 <i>Birth certificates</i> .....	49
3.7.4 <i>Immunizations cards and immunization coverage</i> .....	49
3.8 EXISTING BEST PRACTICES FOR CHILDREN WITH DISABILITIES IN SCHOOLS AND COMMUNITIES. ....	51
3.9 CHALLENGES THAT AFFECT CHILDREN WITH DISABILITIES; COMMUNITY, ENVIRONMENT, AND OTHERS. ....	53
3.9.1 <i>Cultural Challenges</i> .....	54
3.9.2 <i>Education-related challenges</i> .....	55
3.9.3 <i>Health-related challenges</i> .....	56
3.9.4 <i>Socio-economic challenges</i> .....	57
4. SUMMARY, CONCLUSION, AND RECOMMENDATION.....	60
REFERENCES.....	63
ANNEXES .....	66

**LIST OF FIGURES**

Figure 1: Distribution of the quantitative sample by type of household .....	7
Figure 2: Sample Distribution across the seven wards.....	7
Figure 3: Children enrolled in school .....	18
Figure 4: Ways teachers and caregivers communicate about the child .....	20
Figure 5: Reasons why children with disability are not attending school according to their caregivers .....	21
Figure 6: Reasons why children with disability are not attending school as mentioned by caregivers of children without disability .....	22
Figure 7: Where caregivers of children with disability sought medical assistance .....	27
Figure 8: Health service providers in Turkana West Sub-county.....	29
Figure 9: Time taken to the nearest health facility .....	31
Figure 10: Services available to children with disabilities .....	32
Figure 11: Caregivers in support groups and caregivers aware of the existence of support groups .....	34
Figure 12: Caregivers who have been trained in child care.....	35
Figure 13: Caregivers of children with disability who report that their child has play materials and those who see children with disability play with materials .....	36
Figure 14: Caregivers whose children get to play in school and at home .....	37
Figure 15: Caregivers who play with their children and the materials they use to play .....	38
Figure 16: Registration with an organization of people with disability .....	38
Figure 17: Level of comfort of caregivers interacting with and caring for children with disability. ....	45
Figure 18: Caregivers with adequate knowledge of how to interact and care for children with disability ...	46
Figure 19: Where children with disability were born .....	47
Figure 20: Caregivers reporting that the child has a birth notification or birth certificate.....	48

**LIST OF TABLES**

Table 1: School Enrolment by Ward .....	18
Table 2: How parents/caregivers communicate with teachers by ward .....	20
Table 3: Caregivers aware of other children with disability not attending school by ward .....	21
Table 4: Distance to the nearest school a child with disability can attend by Ward .....	23
Table 5: Challenges in accessing education by children with disabilities .....	24
Table 6: Challenges in accessing education by children with disabilities .....	24
Table 7: WKP Baseline Assessment: School situation in Turkana West Sub-County .....	27
Table 8: Where caregivers of children with disability seek medical assistance by ward .....	28
Table 9: Time to nearest health facility according to caregivers by ward .....	30
Table 10: Caregivers views of provision of health services for children with disability .....	31
Table 11: Challenges Caregivers Face Accessing Health Services .....	32
Table 12: Services available for caregivers of children with disability by ward .....	33
Table 13: Types of disabilities caregivers were aware of .....	39
Table 14: Causes of disability .....	40
Table 15: Caregivers knowledge of and attitude towards children with disability .....	41
Table 16: Community practices towards children with disability .....	43
Table 17: Rights of children with disability .....	44
Table 18: Caregivers with adequate knowledge to care for children with disability by ward .....	45
Table 19: Where children with disability were born by ward .....	48
Table 20: Children with a birth notification by ward .....	49
Table 21: Children with a birth certificate by ward .....	49
Table 22: Children with immunization cards by ward .....	50
Table 23: Immunizations children with disability had received by ward .....	50
Table 24: Challenges children with disability face according to caregivers of children WITH disability .....	53
Table 25: Challenges children with disability face according to caregivers of children WITHOUT disability .....	54

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**ACRONYMS AND ABBREVIATIONS**


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BOM	Board of Management
CBC	Competency-Based Curriculum
CBM	Christian Blind Mission
CBO	Community-Based Organisation
CDC	Center for Disease Control
CFM	Child Functionality Module
CFS	Child-Friendly Spaces
CHV	Community Health Volunteer
CIDP	County Integrated Development Plan
CRC	Convention on the Rights of the Child
CRPW	Convention on the Rights of People with Disability
EA	Enumeration Area
EARC	Education Assessment and Resource Center
ECDE	Early Childhood Development Education
ECDC	Early Childhood Development Center
FBO	Faith-Based Organisation
FGD	Focus Group Discussion
ID	Identity
IRC	International Rescue Committee
KII	Key Informant Interview
KNBS	Kenya National Bureau of Statistics
KNCHR	Kenya National Commission of Human Rights
KRC	Kenya Red Cross
MoU	Memorandum of Understanding
MTIP	Medium Term Implementation Framework
n	Sample
NEMIS	National Education Management Information System
NGO	Non-Governmental Organisation
NCPWD	National Council of People with Disability
NGEC	National Gender and Equality Commission
OPD	Organisation of People with Disability
OPWD	Organisation of People with Disability
PWD	People with Disability
SNE	Special Needs Education
SPDC	Social Policy and Development Consulting
SW	Social Worker
UNICEF	United Nations Children's Fund
UNCRPD	United Nations Convention on the Rights of People with Disability
WKP	Waldorf Kakuma Project

## EXECUTIVE SUMMARY

This report presents the findings of a data collection exercise commissioned by the Waldorf Kakuma Project (WKP), targeting households with and without children with disability, in Turkana West Sub County. The data collection was an activity within the BMZ-funded project, *'Improved Access to Inclusive ECDE for Children in Kakuma, Kalobeyei & Host Schools in Turkana West'* implemented by WKP in collaboration with the Christian Blind Mission (CBM).

The purpose of the study was to provide more evidence in data and information that will be used for more effective inclusive education programming. Specifically, the study sought to identify and assess the number of children with disabilities, the types of disabilities, their demographic information, biodata, access, retention, and transition trends of these children in schools, and whether the children with disabilities are enrolled in ECDE centers/schools or not. Data collection took place between June and July 2023.

The primary sampling unit was the household. In each, an adult member, one responsible for day-to-day caregiving responsibilities, was interviewed. A total of 1,247 households in Turkana West Sub County were interviewed. Of these, 839 (67.3%) households with children with disabilities were purposively sampled and another 408 (32.7%) households without children with disability were randomly sampled across the seven wards of the sub-county. Of the children with disability (n=379,44.0%) were boys while (n=483,56.0%) were girls. More than a third of the children (n=327,37.9%) were in Kakuma ward, while Songot ward had the least number of children (n=53,6.1%). The sampling plan for the 408 households without children with disability was developed in collaboration with the Kenya National Bureau of Statistics (KNBS), with the 2019 census framework developed by the KNBS as the basis for our sampling. A multi-stage sampling approach was used to sample caregivers of children without disability.

Qualitative data was collected from 35 Focus Group Discussions (FGDs) with male and female community members, children with and without disabilities, teachers, and boards of management representatives and from Key Informant Interviews with stakeholders. Approximately 168 adults and 112 children from all seven wards were interviewed in FGDs, and approximately 20 stakeholders were interviewed as key informants.

### Study Findings

Findings revealed that children experience varied difficulties across all the levels of the Child Functionality Module (CFM). Furthermore, access to critical equipment and services for children WITH disability was limited, leaving them and their caregivers struggling as they navigated through their day-to-day activities. Overall, children in the refugee camps were reported to have more access to support services compared to those in the host community. This was attributed to the large number of organizations that support interventions within the refugee camps.

However, children in refugee camps were noted to be more vulnerable, especially around their social, emotional, and mental health needs. In the same light, children in the host community had limited access to services and experienced limited access to basic needs and services. This was exacerbated by the relatively higher levels of poverty among the local Turkana community compared to the national average, and low literacy levels among adults which barred them from active participation in diverse socio-economic activities. The following section explores findings on difficulties children in Turkana West Sub-county experience along the CFM.

#### *Sight*

More than a third (n=227,32.6%) of children with disability aged 5-17 years had difficulties seeing, but only a minority (n=37,5%) wear glasses or contact lenses. The proportion of girls with disability, who had difficulty seeing was 31.1% while that of boys was 34.4%. Similarly,

while (n=40,31.7%) of the children aged 2-4 years have difficulties seeing, very few (n=2,1.6%) of them wear glasses. More than a third of boys with a disability, 36.1%, aged 2-4 years, and a quarter of girls, 25.9% had difficulties seeing. Yet, more than half of those with glasses or contact lenses reported that they did not experience any difficulty seeing, which points to the ability of these devices to improve the children's ability to see. Across wards, Songot had the highest proportion of children, 5-17 years with seeing difficulties (n=30,65%), while Nanaam had the least proportion (n=15,20%). Similarly, Songot ward had the highest proportion of children 2-4 years with difficulties seeing, while Nanaam ward had the least.

### *Hearing*

More than a third (n=244,35.8%) of children with disabilities aged 5-17 years, experience difficulties hearing sounds like people's voices and music. The proportion of boys with hearing difficulties was 34.8% while that of girls was 36.9%. However, only (n=52,7.1%) of children in this age category use a hearing aid. But even when using one, a majority of them (n=41,78.9%) still experience difficulties hearing people's voices and music. This finding suggests that the few hearing aids accessible to children aged 5-17 years may not be functional. Songot ward had the highest proportion of children 5-17 years experiencing hearing difficulties (n=27,58.7%), while Nanaam ward had the lowest proportion (n=19,24.7%).

Similarly, about a third (n=39,32.5%) of children aged 2-4 years had difficulties hearing sounds like people's voices and music. The proportion of boys with this difficulty was 39.4% and that of girls was 22.4%. However, only (n=8, 6.3%) of children in this age group used a hearing aid, with half of them reporting that even with the hearing aids they still experience difficulties hearing. For children aged 2-4 years, Lopur ward had the highest proportion of children with hearing difficulties (n=12,57.1%) while Nanaam had the lowest proportion (n=1,9.1%).

### *Walking*

Slightly more than 10% (n=85,11.6%) of children aged 5-17 years use equipment or receive assistance, without which, all face difficulties walking 100 yards (91.4 meters) on level ground. Girls with this difficulty were reported to be approximately 9.5% while boys were approximately 13%. With their equipment or assistance, close to a third of children aged 5-17 years (n=23,27.1%) have no difficulty walking 100 yards (91.4 meters). Findings on children with disability aged 2-4 years show that (n=18,14.1%) use equipment or receive assistance to walk. The proportion of girls with this difficulty for this age category stood at 12.9% while that of boys stood at 14.9%. There were comparatively more children with walking difficulties in Nanaam ward compared to the other wards.

### *Picking up small objects with their hands*

This assessment aspect is relevant for children aged 2-4 years. When compared with other children of the same age, more than half of the children with disability (n=68,53.1%) experience difficulties picking up small objects with their hands. More than half of the girls with disability, 55.6% as well as boys, 51.4% experienced difficulty picking up small objects with their hands. Kakuma ward had a comparatively larger proportion of children with difficulties picking small objects with their hands (n=39,63.9%), followed by Lopur (13, 56.5%), while Kalobeyei had the lowest proportion. According to the medical officers interviewed, when children experience difficulties in picking objects with their hands may suggest that they have not yet developed enough strength, coordination, or dexterity in their fingers and hands, or they may not have had a chance to practice enough with different types of objects, such as small, large, soft, hard, or slippery ones. They observed that another reason could be that the child has a developmental delay or disability, such as autism, cerebral palsy, or Down syndrome, which affects their motor skills and learning.

### *Understanding the caregiver*

Close to half of caregivers (n=59,46.1%) reported that their children aged 2-4 years, with disability, have difficulty understanding them. This was the case for approximately 50% of boys and 40.7% of girls with disability. This suggests that close to half of children aged 2-4 years, with disability, might already have challenges developing their intellectual and mental faculties. More than half of caregivers in Lokichogio, Lopur, and Kakuma wards said their children had difficulties understanding them. In the same light, close to half of caregivers (n=63, 49.2%) said that they face difficulties understanding their children aged 2-4 years when they speak. This was reported by more than half of caregivers in Lokichogio, Lopur, and Nanaam and almost half in Kakuma. This difficulty affected approximately 51.4% of boys and 46.3% of girls with disability.

### *Learning things*

Close to half of children with disability aged 5-17 years (n=330,45%) have difficulty learning things such as how to draw, paint, clean clothes, and bathing among others. This difficulty affected approximately 46.5% of girls and 43.8% of boys with disability. The highest proportion was reported in Lopur (n=74,63.2%) and Kakuma wards (n=161,60.5%). The lowest proportion was recorded in Lokichogio ward (n=21,18.6%). Furthermore, more than half the children aged 2-4 years and with disability (n=74,57.8%) experienced difficulty learning things compared with other children of the same age. This difficulty affected proportionately more boys, 64.9% compared to 48.1% of girls with disability. Kakuma ward registered the highest proportion of children in this age category with difficulties learning things (n=41,67.2%), followed by Nanaam and Songot wards (66.7% respectively). Difficulties in learning according to key informants could result from stress, trauma or emotional problems, exposure to toxins or infections, or even genetic factors.

### *Remembering things*

This assessment aspect is relevant to children aged 5-17 years. More than a third (n=285,38.8%) have difficulty remembering things. Approximately 41% of girls and 37% of boys with a disability experienced difficulty remembering things. Key informants noted that this could also result in learning difficulties. Lopur ward had the highest proportion of children with this difficulty (n=60,51.3%) followed by Kakuma ward where (n=127,47.7%) of children 5-17 years experienced this difficulty. Nanaam ward had the least proportion (n=20,22.5%).

### *Concentration*

This assessment aspect is relevant to children aged 5-17 years. From the findings, more than a third of children (n=262, 35.7%) have difficulty concentrating. About 35% of boys and 37% of girls with a disability experienced difficulty concentrating. Lopur ward had the highest proportion of children experiencing this difficulty (n=64,54.7%) followed by Kakuma (n=121,45.5%). The lowest proportion was recorded in Lokichogio (n=13,11.5%) Difficulty in concentrating may lead to problems in following instructions, completing tasks, or organizing their time, which can affect their independence, self-care, productivity, and clumsy behaviour<sup>1</sup>.

### *Accepting change in routine*

More than a third of children with disability aged 5-17 years (n=249,33.9%) have difficulty accepting change in their routine. This was the case for approximately 34.2% of boys and 33.5% of girls with disability. Lopur ward had a higher proportion of children facing this difficulty followed by Kakuma with (n=108,40.6%). The lowest proportion was recorded in Lokichogio (n=10,8.8%). Children who have difficulties in accepting change in routine may experience more stress, anxiety, frustration, and confusion when faced with unfamiliar or unpredictable situations,

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<sup>1</sup> <https://mentallyhealthyschools.org.uk/mental-health-needs/overactivity-and-poor-concentration/>

which can impair their cognitive, emotional, social, and physical development, as well as their academic performance and achievement<sup>2</sup>

#### *Controlling own behaviour*

Just about a third of children with disability aged 5-17 years (n=240,32.7%) have difficulty controlling their behaviour. This difficulty was experienced by about 34.5% of girls and 31.3% of boys with disability. Lopur ward had a higher proportion of children with this difficulty (n=62,53%) followed by Kakuma ward (n=102,38.3%). The lowest proportion was in Lokichogio ward (n=13,11.5%). Key informants noted that difficulties with self-regulation could result from genetic factors such as ADHD or autism, exposure to stress, trauma, or violence at home or in the community, disability that affects the cognitive, social, or emotional development, or psychological factors, such as having low self-esteem, anxiety, depression, or anger issues.

#### *Making friends*

Close to half of children with disability aged 5-17 years (n=209,47%) have difficulty making friends. This difficulty affected proportionately more girls, 30.2% compared to 27.1% of boys with disability. Lopur ward had the highest proportion (n=58,49.6%) of children experiencing this difficulty according to caregivers, followed by Letea ward with (n=14,31.1%). Difficulties making friends could be a result of low self-esteem, stress, trauma, or violence at home or in the community.

#### *Seem very anxious, nervous, or worried*

Caregivers were asked how often their children seemed anxious, nervous, or worried, to which about two-thirds of them, (n=460,62,7%) reported that their children often seemed very anxious, nervous, or worried. No major differences were seen across genders, even though this difficulty was experienced by approximately two-thirds of children with disabilities. High proportions of caregivers reporting that their children experienced this difficulty were recorded in Kalobeyei ward (n=52,96.3%), Lopur ward (n=100,85.5%), Kakuma (n=218,82%) and Songot ward (n=41,82%). Experts note that anxiety is a natural reaction to challenging situations<sup>3</sup>. However, children with disability or chronic conditions are more likely than other children to experience anxiety.

#### *Seem very sad and depressed*

More than two-thirds of caregivers (n=461,62.8%) said that their children often felt very sad and depressed. This was mirrored in the proportion of girls and boys with disability reported to be experiencing this difficulty. Similarly, caregivers in Kalobeyei ward recorded the highest proportion of children experiencing this difficulty (n=53,98.1%), followed by Lopur ward (n=100,85.5%), and Kakuma ward (n=224,84.2%). Reports indicate that children with disability or chronic conditions are more likely to experience low mood and depression than their peers. because they might, often be in pain, feel different from their peers, feel that their condition gets in the way of daily life, experience bullying, struggle with school work, or experience difficult medical procedures<sup>4</sup>.

#### *Playing*

More than half of children aged 2-4 years (n=74,57.8%) have difficulties playing compared to children of the same age. Across genders, 55.4% of boys and 61.1% of girls with disability also experienced difficulties playing. Kakuma ward had the highest proportion of caregivers (n=44,72.1%) reporting that their children experienced difficulty playing followed by Nanaam ward (n=7,58.3%). The lowest proportion was in Kalobeyei as reported by (n=1,16.7%) of

<sup>2</sup> <https://www.caudwellchildren.com/setting-a-routine-for-disabled-children/>

<sup>3</sup> <https://raisingchildren.net.au/disability/mental-health-physical-health/anxiety/anxiety-children-with-disability>

<sup>4</sup> <https://raisingchildren.net.au/disability/mental-health-physical-health/depression/depression-children-with-disability>

caregivers. Key informants noted that difficulties playing could result from developmental delays or disorders, such as autism, dyspraxia, or intellectual disability, that affect the children's cognitive, social, emotional, or motor skills.

#### *Kick, bite, or hit other children*

Findings show that (n=56,43.8%) of children with disability kick, bite, or hit other children the same or less, compared to other children of the same age. Slightly more girls 48.2% compared to 40.5% of boys with a disability kick, bite, or hit other children the same or less compared to other children their age. There were no fundamental differences across the wards. This suggests that children with disability aged 2-4 years in the Turkana West sub-county exhibit normal physical aggression, which is a normal way of expressing anger, frustrations, or fear for such children who may have limited language skills

#### *Self-care such as feeding or dressing*

This assessment aspect was relevant for children with disability aged 5-17 years. Overall, more than a third of the children (n=291,39.6%), have difficulties with self-care, including dressing and feeding. Proportionately more boys, 40.6% of boys compared to 38.5% of girls with a disability experienced this difficulty. More than half the caregivers in Songot (n=26,52%) reported that their children faced this difficulty. The same was reported by (n=128,48.1%) in Kakuma and (n=21,46.7%) in Letea ward.

#### *Difficulty being understood while speaking in the household*

This assessment aspect was relevant for children with disability aged 5-17 years. Findings show that (n=296,40.3%) have difficulty being understood when they speak in their household. This affected proportionately 42.3% of boys and 37.8% of girls with disability. This was reported by more than half of the caregivers in Kakuma (n=135,50.8%) and by (n=11,20.4%) in Kalobeyei ward. In comparison, (n=315,42.9%), have difficulties being understood when they speak outside their households. This was reported by (n=66,56.4%) of caregivers in Lopur ward, and by (n=138, 51.9%) in Kakuma. Difficulties being understood could result from speech disorder, which is a problem with the production or fluency of speech sounds. Speech disorders can affect the way children pronounce words, the rhythm and flow of their speech, or the quality and tone of their voice<sup>5</sup>.

#### *Education situation*

According to caregivers more than two-thirds of children WITH disabilities (n=556,64.5%) were enrolled in school at the time of this study. This was mirrored across genders. It was also noted that at least about half of children with disability were enrolled in schools except in Letea ward where just about a third (n=17,29.8%) of children with disability were enrolled in schools. More than half of children with disabilities and in school (n=314,56.4%) were at the primary school level, while slightly more than a third (n=200,36%) were in preschool. Key informants however noted that the number of children with disability not in school could be higher in the remote areas of the sub-county. Transition from one level to another for children with disability was reported to be low across all levels. This was largely attributed to a lack of skilled teachers who should prepare children for transition to upper levels of education.

#### *Children not in school*

For children not in school, caregivers gave varied reasons why children with disabilities were not enrolled in school. Lack of schools with the necessary facilities was the most mentioned reason (n=156,26.3%) followed by the absence of a special school mentioned (n=107,18%). This was followed by the reason that the child was too young to be in school (n=97,16.4%), and inability

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<sup>5</sup> <https://www.cdc.gov/ncbddd/developmentaldisabilities/language-disorders.html>

to walk to school (n=80,13.5%). The high cost of education was mentioned by (n=54,9.1%). Another (n=34,5.8%) reported that there was no need to educate the children.

Overall, distances to school, lack of specialized schools and special needs teachers, unfriendly school environments and infrastructure, and the high cost of education prevented children with disability from attending school according to key informants. These were exacerbated by the likelihood of stigmatization and negative community attitudes toward children with disability. The school feeding programme was however noted to be a major attraction to schools.

#### *Health situation*

Study findings show that health facilities are gaining prominence as preferred healthcare providers for caregivers of children with disabilities. Health facilities received most mentions (n=650,47.2%), from caregivers as the preferred source of advice the last time their child needed health care. They received the most mentions in Kalobeyei (93.7%), Kakuma (62.7%), Lopur (58.6%), and Nanaam wards (42.3%), and the least mentions in Letea (14%), Songot (17%), and Lokichogio 32.2%. Others mentioned were relatives (n=180,13.1%), visiting community health workers (n=162,11.8%), friends/ neighbours (n=150,10.9%), chemists or pharmacy (n=120,8.7%), religious leaders (n=95,7%) and traditional healer (n=15,1.1%). But even with the low mention, discussions with community members in FGDs revealed that traditional medicine was still very common and popular in Turkana West, with many people preferring to seek health care from traditional healers. This was because they were accessible, cheaper, and had the medicines people needed.

Physical access to health facilities was reported to be in the range of between 20 minutes to an hour's walk for most of the caregivers. The nearest health facility was more than an hour's walk for more than half (n=65,52.4%) of caregivers in Lokichogio and about an hour's walk for n=30,56% of the caregivers in Songot ward. Less than half of caregivers of children with disability walked for less than 10-30 minutes to reach the nearest health facility as reported by (n=358,41.5%). Another (n=166,19.3%) walked for between 30 to 45 minutes while (n=135,15.7%) walked for between 45 to 60 minutes. A few caregivers (n=88,10.2%) reported that they walked for about an hour, and another (n=115,13.3%) walked for more than an hour. Besides the long distances to health facilities, other challenges mentioned in accessing health services include lack of specialized health services, lack of specialized personnel, inadequate equipment and medicine, and high cost of health services.

#### *Psychosocial and safety support systems*

Counselling and psychosocial support services were the most mentioned by caregivers (n=279,25.5%) followed by nutritional support reported by (n=229,21%). Counselling and psychosocial support received more mentions in Kalobeyei and Letea wards. Others mentioned were child protection and case management and referral services, play materials, and play areas. However, almost all caregivers of children with disabilities (n=826,98.5%) were not members of a parental support group. The psychosocial and safety support system in the sub-county was however revealed to be weak and ill-equipped and therefore unable to effectively support the care and protection of children with disabilities. This was further compounded by a negative attitude towards people and children with disability among community members, some of them regarding children with disability as a curse and a bad omen.

#### *Training in the care of children with disability*

Findings show that a majority of caregivers with children WITH disabilities (n=710,84.6%) across all the seven wards had not benefitted from training in caring for their child. Those who had attended some training, (n=129,15.4%), were trained by an NGO, an international organization, or the county government. It is further noted that almost all caregivers of children without disability had not attended any training to learn something about children with disability,

as reported by (n=384,94.1%). Lack of community knowledge and understanding of children with disability was noted to have serious consequences on the children with disability and their families thus circumferencing the already existing stigma. Interviews with key informants, for example, noted that children with disability may fail to enrol in school because of stigma, discrimination, bullying in the community, and lack of financial support, learning facilities and materials, and trained staff.

#### *Play materials*

More than half of the caregivers of children with disability (n=508,58.9%) reported that their children had play materials at their homes, while a significant (n=354,41.1%) said their children did not have any play materials. Discussions with children reported that children with disability are normally involved in song and storytelling, and to an extent physical games such as football for children with mild disability. In most cases, however, children with disability are often excluded from most games that children play due to the disability challenges.

#### *Registration and birth of children*

A majority of caregivers said that their children were not registered with any organization for people with disability as reported by (n=794,92.1%). Another (n=25, 2.9%) did not know if their children were registered. Of the 43 caregivers, who reported that their children were registered, 35 of them were registered with the NCPWD. More than half of caregivers (n=448,52.0%) indicated that their child was born in a health facility. The other close to half (n=409,47.5%) reported that their child was born at home. Letea Ward had the highest number of caregivers reporting that their child was born at home (n=56,98.3%), while Nanaam Ward had the lowest number reporting home delivery (n=37,36.7%). A few did not know as they were foster caregivers.

Half of the caregivers (n=435,50.5%) reported that their children did not have birth notifications, compared to (n=411,47.7%) who had one. A majority in Letea ward (n=53,93%) did not have a birth notification. A small number (n=16,1.8%) did not know if the child had a birth notification. This finding was mirrored in the finding about the birth certificates to which (n=442,51.3%) of caregivers reported that their children did not have, while (n=408,47.3%) said that the children had birth certificates. A majority in Letea ward (n=55,96.5%) and in Kalobeyei (n=49,81.7%) did not have a birth certificate. More than half in Kakuma, Nanaam, Lopur, and Songot wards reported that their children had a birth certificate.

From the findings, a few good practices were reported including, the school feeding programme which pulls and keeps children enrolled in schools, Community Health Promoters (CHPs), and social workers who made frequent home visits to households of children with disability, the engagement of people with disability in community activities including leadership positions and as teachers, which motivated children with disability, the County Persons with Disability Act 2018, which sets the basis for the care and protection of people with disability in the county, social welfare officers and a board within the Turkana County government, who deal specifically with matters disability, and the capitation grants for special needs education learners which supports their education.

From the findings, this study puts forth some recommendations, which could contribute to improving the situation of children with disability in Turkana West Sub County and Turkana County as a whole.

1. **Awareness creation:** The national and county governments and other development actors may need to invest more time and resources in sensitizing the community on issues about disability. The study revealed that high levels of misconceptions and

- misunderstanding on disability, which if addressed could lead to improved care and protection of children with disability.
2. **Build Capacity for functional assessments-** Organisations intervening in disability issues ought to focus on building and enhancing the capacity of front-line caregivers, including parents and other caregivers, teachers, CHPs, and social workers to conduct functional assessments for children WITH disability. Functional assessments are the very first step in determining the treatment, care management, and education pathway of a child with disability.
  3. **Enhance and support outreach programmes:** The government and development partners ought to enhance and promote community outreach programmes. These were reported to be effective in reaching the hard-to-reach populations. When they are complemented by referrals and reverse referrals, they benefit many more children, otherwise unable to reach the health facilities. More outreach programmes in number, scope, and frequency should be supported, and designed to cover the special needs of children with disability, registration, and general health screening among others.
  4. **Ensure appropriate timing for screening of children.** Partners, and other agencies involved in screening children for disability might by design target most of the screening to take place when there is pasture (considering most of these communities are pastoralists and nomads) and when most households are settled in their homes. This will likely lead to more children being screened.
  5. **Strengthen coordination among organisations in Turkana West Sub-County to strengthen the referral system.** While multiple organisations were actively intervening on issues around disability in Turkana West Sub-County and largely in the refugee communities, many tend to work in silos, save for occasional networking meetings where they only shared updates on what each organization did. This, unfortunately, seldom influenced the choice of interventions across the organizations. Closer coordination of actors might lead to more impact from interventions. Besides, this may also strengthen the referral system within Turkana West Sub County if a clear pathway could be mapped showing which organization did what and where. Within the camps, this can be championed by UNHCR, in collaboration with the (national and County governments) Department of Children Service (DCS), while the DCS could champion the same across the host communities.
  6. **Existing and new infrastructure should be disability friendly.** The county government may, in line with the provisions of the Persons with Disability Act ensure that the existing and upcoming infrastructure especially in schools, are disability friendly to improve access, retention, and transition for children with disability. For any new developments, for example, the county government should target construction plans and approvals to ensure that they are inclusive and disability friendly. Existing infrastructure should similarly be renovated to make them disability friendly, and hence offer reasonable accommodation and access.
  7. **Invest in solar energy to power learning and health facility equipment:** The national and county governments ought to plan and support the installation and maintenance of solar power in schools and health facilities to ensure the uninterrupted running of key equipment necessary for the care and protection of children with disability. With power supply reported to be erratic and costly, health facilities often go for days without power which affects the shelf life of drugs including vaccinations. Education institutions on the other hand lack power that can support the use of modern technology that can support learning by children with disability.
  8. **Educate caregivers on self-care and caring for children with disability.** Organisations working with households for children with disability ought to prioritize educating children on self-care. Caregivers were reported to face numerous challenges including stigma from other community members. This takes a toll on the caregivers which often causes some

of them to hide their children from the public. Skills on, for example, self-acceptance and how to care for children with disability would help them to cope.

9. **Lobby for the linking of the NCPWD database with the Child Protection Information Management System (CPIMS)** to improve child protection data for children with disability. The government may explore this possibility with Turkana West sub-county as a pilot. This will aid in the collection of timely and up-to-date data on children with disability.
10. **Teachers ought to be trained and encouraged to apply inclusive pedagogies when teaching.** Adoption of simple inclusive pedagogies such as speaking slowly while teaching might go a long way in ensuring children with disability and other learning difficulties are not left behind in learning. Capacity building for teachers supported by programme partners may therefore aim to equip teachers with skills that can enable them to integrate methods that enhance learning by children with disabilities during their lessons.
11. **Support local organisations of people with disability to enable them to complement the work done by organisations intervening in disability issues.** Organisations for people with disability have the best chance to champion the rights of people with disability. The focus for organisations, therefore, ought to be on building an agency for people with disability and supporting them to champion the rights of children and adults with disability.
12. **Involve more people with disability in community activities including leadership:** People with disability who perform critical roles such as teachers, doctors, counsellors elected leaders are normally seen as role models for children with disability. This ought to be encouraged by governments and development organisations, to give children with disability hope.
13. **Consider more investments in CHPs and Social workers.** In an environment with a poor transportation network, caregivers of children with disability relied more on CHPs, and social workers for most information on the care and protection of children with disability. CHPs and social workers can easily reach out to more households and disseminate relevant information. CHPs are also a strategic avenue for the collection of timely and accurate data on disability in the sub-county.
14. **Support the establishment and strengthening of social support groups for caregivers.** These have the potential to provide mutual support, connection, knowledge, and experience-sharing opportunities for caregivers of children with disability
15. **There is a need for further research.** More research is needed to gather similar data for all other sub-counties in Turkana County. In addition, a deeper understanding of the socio-economic factors and how they impact disability would be essential in designing long-term disability support programmes in Turkana County.

## 1. INTRODUCTION

### 1.1 Waldorf Kakuma project

Waldorf Kakuma Project (WKP) is a non-governmental organization that aims to transform the lives of children and adolescents affected by crises through psychosocial support and education. WKP runs child development, education, and child protection programs in Kakuma, Kalobeyei, and the surrounding host communities. WKP believes children can be empowered through education to achieve their dreams despite their circumstances. WKP has been operating in Kakuma Refugee Camp since January 2014, and in other parts of Kenya, delivering interventions in Child Protection, emergency education, psychosocial support, and education. Concerning people with disabilities, WKP has gained experience following previous cooperation with CBM, but also through cooperation with Humanity & Inclusion (HI) in the inclusion of children with disabilities in the Child-Friendly Spaces (CFSs) including the Early Childhood Development and Education (ECDE) centers.

WKP has worked with most ECDE centers in Turkana West Sub-County, implementing education interventions with UNICEF since 2018. In cooperation with CBM, WKP aims to expand its capacities for the inclusion of children with disabilities moving forward, under the BMZ-funded project on Improved Access to Inclusive Early Childhood Care and Schooling for Children with Disabilities in Refugee (Kakuma/Kalobeyei camps) and host communities in Turkana West Sub County. This data collection was carried out under this project. Furthermore, WKP has an ongoing MoU with the Turkana District Education Department and continues to work with appropriate and experienced education staff familiar with the context in Turkana West Sub County. In this respect, WKP already has good relationships with most of the educational institutions in the project's target area. Due to the long-standing work in the fields of education and child protection, WKP has established a good working relationship with the local administration, a factor that adds value to WKP interventions.

### 1.2 Study purpose and objectives

To ensure more focused programming and targeted programs, WKP commissioned a household survey targeting households with children with disability in Turkana West Sub County and households without children with disability. The purpose of the study was to provide more evidence in the form of data and information that will be used for more effective inclusive education programming. Specifically, the study sought to identify and assess the extent of children with disabilities, their demographic information, biodata, the type of disabilities, access, retention, and transition trends of these children in schools, and whether the children with disabilities are enrolled in ECDE centers or not. Specifically, the study sought to,

1. Provide a clear picture of the educational situation of children with disability in Turkana West Subcounty, particularly enrolment, transition rate, barriers to the education of children with disability as well as children with disability not enrolled in schools.
2. Assess knowledge attitudes and perceptions of parents/caregivers, children, and communities on disability and propose interventions that can enhance behavioural change/positive perception of these children from the community.
3. Gather information about existing collaborative psychosocial and safety support systems for children with disabilities within families, communities, and, schools.
4. Access the provision of needed health services for children with disability, home-to-school referral systems for children with disability, and how accessible the health centers are.
5. Establish whether the children are registered with NCPWD, and what support systems are available in the community for the same children.

6. Establish if children with disability have received all the vaccinations, and if they are supported with nutritional plans from the local health centers.
7. Establish existing best practices for children with disabilities in schools and communities.
8. Establish barriers/challenges that affect Children with disabilities from the community, environment, and others.

### 1.3 The context

The Convention on the Rights of the Child (CRC) recognizes the human rights of all children, including those with disabilities. In addition, the Convention on the Rights of Persons with Disabilities (CRPD) provides a powerful new impetus to promote the human rights of all children with disabilities. UNICEF notes that about 15 percent of the world's population or approximately one billion people have some form of disability<sup>6</sup>. About a quarter of them or approximately 240 million are children, 10 percent of whom are in Eastern and Southern Africa<sup>7</sup>.

Kenya ratified the UNCRPD in 2008. Disability rights are provided for under Kenya's 2010 constitution and the 2003 Persons with Disabilities Act, amongst others. Some individual counties, including Turkana<sup>8</sup>, have their disability legislation. The ministry of Labour and Social Protection<sup>9</sup> currently holds the mandate to promote and protect the rights of persons with disabilities, while the National Council for Persons with Disabilities takes a lead role in the follow-up and enforcement of the law. The Persons with Disabilities Act established the National Council for Persons with Disabilities (NCPWD) in 2004, currently under the Ministry of Labour and Social Protection. NCPWD duties include monitoring compliance with the law, formulating, and establishing measures and policies to ensure equitable opportunities for people with disabilities.

Overall, persons with disabilities are more likely to be living in poverty than people without disability, Reports further indicate that people with disabilities experience stigma and discrimination which excludes them from economic and social activities and full participation in life. People with intellectual disabilities, and psychosocial disabilities, are particularly affected and vulnerable to violence<sup>10</sup>. This same report by the Institute for Development Studies further notes that children with disabilities are less likely to be enrolled, retained, or complete their education, in comparison to children without disabilities (44% completed primary school in comparison to 60%), as a result of factors such as high cost, stigmatization, inappropriate curricula, poorly equipped institutions of learning, overcrowding, and insufficiently trained teachers. Significant numbers of in-school children with disabilities are in special schools and units, rather than in mainstream schools or institutions that provide inclusive education.

To ensure alignment with the UNCRPD's inclusive education principle, the National Special Needs Education Policy Framework of 2009 was updated in 2018 to the Sector Policy for Learners and Trainees with Disabilities. To provide education services to learners with disabilities at all levels of school, from early childhood to university, this new Policy focuses on the implementation of inclusive education and reasonable accommodation to learners with disability<sup>11</sup>

Project documents show that a direct comparison in the education sector between host communities and camps in Turkana West Sub County shows that the basic facilities in the refugee

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<sup>6</sup> <https://www.unicef.org/disabilities>

<sup>7</sup> <https://data.unicef.org/topic/child-disability/overview/>

<sup>8</sup> [https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15508/DID%20Kenya%20SITAN\\_June%202020.pdf?sequence=1](https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15508/DID%20Kenya%20SITAN_June%202020.pdf?sequence=1)

<sup>9</sup> The name of the parent ministry can change with the realignment of governance structures and renaming of ministries.

<sup>10</sup> [https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15508/DID%20Kenya%20SITAN\\_June%202020.pdf?sequence=1](https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/15508/DID%20Kenya%20SITAN_June%202020.pdf?sequence=1)

<sup>11</sup> Disability Inclusive Development Kenya Situational Analysis, UKAID, June 2020 update

camps are overall, better than those in the host communities. This is reflected in, among other things, a slightly better supervision ratio of the learners. There is also a special resource center (Education Assessment and Resource Centers (EARC) in Kakuma town, about two to three kilometers away from the Kakuma refugee camp and four kilometers from the Kalobeyei refugee camp, which carries out the identification of and support for children with disabilities. The center is managed by the Lutheran World Federation (LWF). This is not the case for the host communities. The Turkana County Government has only one EARC in Lodwar, which is about 120 kilometers from Kakuma. The center is reported to be extremely underequipped and understaffed.

The UNHCR 2022 report on Education<sup>12</sup> observes that education is a basic human right, enshrined in the 1989 Convention on the Rights of the Child and the 1951 Refugee Convention. Furthermore, the report indicates that education protects refugee children and youth from forced recruitment into armed groups, child labour, sexual exploitation, and child marriage. It also strengthens community resilience. Education empowers by giving refugees the knowledge and skills to live productive, fulfilling, and independent lives. Education, further enlightens refugees, enabling them to learn about themselves and the world around them while striving to rebuild their lives and communities.

The right to education is acknowledged as an overarching right in Kenya. It is explicitly provided for in Article 53(b) of the Kenya Constitution 2010 which guarantees the right to free and compulsory basic education for every child. In addition, article 54 of the Constitution specifically targets persons with disabilities. It provides any person with a disability a right to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of that person<sup>13</sup>. Furthermore, Kenya's Vision 2030 social pillar recognizes disability mainstreaming as a flagship project under the Third Medium Term Implementation Framework (MTEF)<sup>14</sup>

Special needs education in Kenya is provided in special schools, integrated units, and inclusive settings in regular schools. However, the majority of children with disabilities are not in schools. Findings from the National Economic Survey of 2019, show that children with disabilities from poor backgrounds are unable to access technology-mediated teaching and learning via radio, television, and the internet, a situation that widens the inequality gap in equity, access, and quality of education. This is exacerbated by the understanding that most households with persons with disabilities live in poverty, with limited ability to finance school-related expenditures<sup>15</sup>. Overall, this hinders the attainment of Sustainable Development Goal Four (4) on inclusive and equitable education and the promotion of lifelong learning opportunities for all<sup>16</sup>.

The County government of Turkana developed the County Persons with Disability Act 2018, to provide for the rights, habitation, and rehabilitation of persons with disabilities; to achieve equalization of opportunities for persons with disabilities, to establish the county board for persons with disabilities, and connected purposes<sup>17</sup>. Despite this initiative, available data shows disability was yet to be fully mainstreamed in the county operations. A study carried out by the National

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<sup>12</sup> <https://www.unhcr.org/631ef5a84/unhcr-education-report-2022-inclusive-campaign-refugee-education>

<sup>13</sup> Government of Kenya (2010). The Constitution of Kenya 2010

<sup>14</sup> Government of Kenya (2018) Third Medium Term

<sup>15</sup> Kenya National Bureau of Statistics (2019): National Economic Survey. KNBS, Nairobi.

<sup>16</sup> United Nations, (2015). Transforming Our World: The 2030 Agenda for Sustainable Development. New York: UN Publishing

<sup>17</sup> <http://kenyalaw.org/kl/fileadmin/pdfdownloads/Acts/TurkanaCountyPersonswithDisabilitiesAct2017.pdf#:~:text=THE%20TURKANA%20COUNTY%20PERSONS%20WITH%20DISABILITY%20BILL%2C%202017,as%20the%20Turkana%20county%20persons%20Short%20Title%20and>

Gender and Equality Commission (NGEC)<sup>18</sup> reports that communities gave little or no support to children with disabilities to receive an education. This was due to several factors including socio-cultural factors, poverty, lack of awareness, stigmatization, and negative attitudes. These children face discrimination from both their families and their communities.

Other reports<sup>19</sup> show that of the estimated 83 million forcibly displaced people worldwide, 42% are children, and as many as 15–20 percent are people with disabilities. Children with disabilities in refugee camps are especially vulnerable to stigmatization, re-traumatization, exclusion, isolation, and violence. Furthermore, barriers stemming from their disability limit their abilities to access education, and essential services, form relationships with their peers, and foster healthy psychosocial well-being. For disabled refugee children, education can offer additional benefits such as reducing marginalization because of the stigma around disabilities.

The Turkana County Integrated Development Plan (CIDP) (2018-2022)<sup>20</sup> notes that children in Turkana (6-13 age group) are less likely to access primary education, with only 50% enrolled (53.2% for boys, 46.6% for girls), compared to the national average of 92.5% (94.6% for boys and 90.5% for girls). Furthermore, consistent investments in Early Childhood Development Centers (ECDCs) have raised the number of children enrolling for basic education in Turkana by over 50,000 children in the last 5-10 years. For example, the 2023-2027 CIDP<sup>21</sup> documents that ECDE enrolment increased from 84,832 to 155,300 learners in 2022, inclusive of refugee children.

According to the report, the number of qualified ECDE teachers employed by the County government has progressively increased from 150 in 2013 to 545 in 2022 resulting in a teacher-pupil ratio of 1:285. The number of ECDE centers has also gone up from 662 in 2013 to 989 operational centers in 2022. These include 37 private ECDEs and 19 ECDE centers located in Kakuma Refugee Camp. A total of 260 modern public ECDE centers had been constructed as of 2022 up from 60 in FY 2013/2014. This had overall decreased the distance children need to travel, thus increasing the enrolment rates.

Further, the 2018 -2022 CIDP observed that many children were still learning in mobile nursery schools, in manyattas, or under trees, especially in the host communities. In addition, many children drop out of school due to high costs associated with learning, which include school uniforms, tuition fees for those in private institutions, and other levies. Other factors include teenage pregnancy, household obligations, and inadequate infrastructure. While schools in refugee camps were more accessible to the children, they also faced several challenges, including limited funding, overcrowding, lack of updated learning materials, insufficient teacher training, and poor technology.

About access to health, there are a small number of specialist government hospitals which provide screening and rehabilitation services to persons with disabilities but these services are limited in the rural areas. The government has in the past provided training and sensitisation on disability issues at various levels to health workers, especially to those working with children by setting up disability mainstreaming committees in 2012. These committees have a mandate to train and sensitize the health workers on the rights of persons with disabilities. According to Kenya National Commission on Human Rights (KNCHR) 2016 report, the government of Kenya has set up community-based rehabilitation programmes for persons with disability, whose role is early

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<sup>18</sup> National Gender and Equality Commission (NGEC) (2016) Access to Basic Education by Children with Disability in Kenya.

<sup>19</sup> <https://conflictandhealth.biomedcentral.com/articles/10.1186/s13031-022-00486-6>

<sup>20</sup> <https://devolutionhub.or.ke/resource/turkana-county-integrated-development-plan-2018-2021>

<sup>21</sup> <https://turkana.go.ke/download/final-turkana-cidp-iii-2023-2027/>

identification, community sensitization, and intervention services<sup>22</sup>. The extent to which this has been implemented in the host community of Turkana County was out of the scope of this research and only further research can verify.

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<sup>22</sup> Kenya National Commission on Human Rights (KNHCR) 2016

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## 2. STUDY SCOPE, APPROACH AND METHODOLOGY

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### 2.1. Scope

This study was carried out in Turkana West Sub-County of Turkana County. All seven wards in the sub-county were targeted for data collection. Quantitative and qualitative methods were used to collect data. Quantitative methods targeted households with and without children with disabilities, while qualitative methods targeted community members, children, teachers, chiefs, ward education officers, child protection officials, partner organizations, and representatives of ECDE centers' Boards of Management (BOMs). As part of qualitative methods, relevant literature was reviewed in line with the study objectives.

### 2.2 Sampling plan

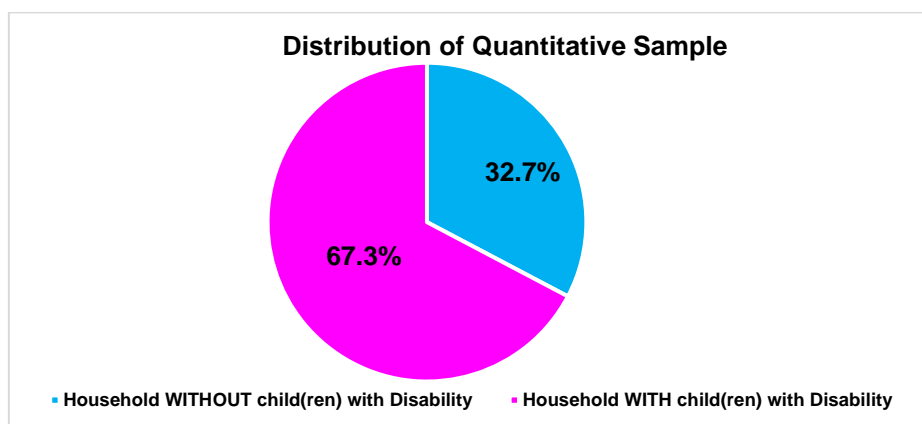
The primary sampling unit was the household. In each household, an adult member, one responsible for day-to-day caregiving responsibilities was interviewed. Households with children with disabilities were purposively sampled based on information that Waldorf Kakuma Project (WKP), local social workers had from their interventions targeting households, and information shared by organizations of people with disabilities (OPWD), chiefs, and other local leaders. Caregivers of children with disabilities also guided the enumerators to other households with children with disabilities. The study aimed at reaching as many households with children with disabilities as was practically possible.

Households without children with disabilities were randomly sampled. The 2019 census framework developed by the Kenya National Bureau of Statistics (KNBS) was used to draw the sample. A multi-stage sampling approach was used to sample these caregivers. Firstly, sample Enumeration Areas (EAs) were randomly picked from each of the seven wards in the Turkana West sub-county. Next, a sample of households was proportionately allocated to each of the sampled EAs. Using EA maps from the KNBS, enumerators identified a starting point from where they commenced the systematic sampling of households to be interviewed until the target number of households in each EA was reached. The sampling plan for households of children without disabilities was developed in collaboration with the KNBS.

### 2.3 Data collection and samples reached

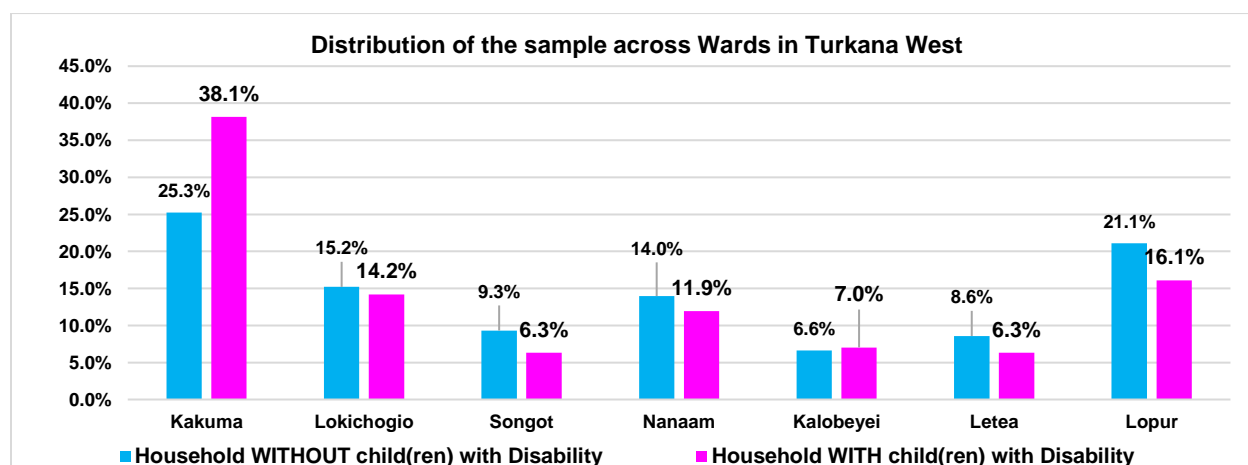
Data was collected using electronic devices, which improved the accuracy and overall quality of data collected and allowed for its timely submission to a central server. Enumerators were drawn from among WKP social workers and seasoned research assistants recruited from the target wards. Following the training, a pilot exercise was carried out to test the data tools and enable the data collection team to practice handling the tablets and the administration of interviews. The data collection team was deployed in two teams, one covering the Kakuma cluster and another the Lokichogio cluster. Each team had a lead enumerator reporting directly to a team supervisor.

Overall, 1,247 households were interviewed a majority of them (n=839,67.3%) being those with children with disabilities while those without disability accounted for (n=408, 32.7%) as seen in the figure below.



**Figure 1: Distribution of the quantitative sample by type of household**

Study findings further show that this sample was distributed across the seven wards of Turkana West Sub-County as seen in the table below.



**Figure 2: Sample Distribution across the seven wards**

Quantitative data was also collected from existing reports and data on children with disabilities in Turkana, including but not limited to enrolment rates in school.

Qualitative data was collected from 35 Focus Group Discussions (FGDs) with male and female community members, children with and without disabilities, teachers, and board of management representatives. In addition, representatives from partner organizations, organizations of people with disabilities, local chiefs, ward education officers, and other relevant government officers were interviewed in Key Informant Interviews (KII). In total, approximately 168 adults and 112 children from all seven wards were interviewed in FGDs. Approximately 20 stakeholders were interviewed as key informants. Quantitative data analysis was done using SPSS, while ATLAS. ti was used to analyse qualitative data. Two SPDC staff supported the facilitation and note-taking in the FGDs while KIIs were carried out by the consultants.

Field data was collected between June and July 2023, with the quantitative data collection taking about 30 days. The FGDs run concurrently with the quantitative data collection. Key informant interviews were carried out in July and lasted about 5 days. All interviews were physical. A stakeholders briefing was done before the fieldwork in June 2023, while dissemination of findings was done in February 2024

### 3. STUDY FINDINGS

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Findings revealed that children experience varied difficulties across all the levels of the Child Functionality Module (CFM). Furthermore, access to critical equipment and services for children WITH disability was limited, leaving them and their caregivers struggling as they navigated through their day-to-day activities. Overall, children in the refugee camps were reported to have more access to support services compared to those in the host community. This was attributed to the large number of organizations that support interventions within the refugee camps. Furthermore, children in refugee camps were also noted to be more vulnerable, especially in their social, emotional, and mental health needs.

In the same light, children in the host community had limited access to services and experienced limited access to basic needs and services. This was exacerbated by the relatively higher levels of poverty among the local Turkana community compared to the national average, and low literacy levels among adults which barred them from active participation in diverse socio-economic activities. The following section explores findings on difficulties children in Turkana West Sub-County experience along the CFM.

#### 3.1 Assessment of Children with Disability (CFM)

This section presents the findings of the child functionality assessment that was carried out using the Child Functionality Module (CFM) developed by UNICEF and partners. While the project had assessed a majority of children with disability in their programme, additional data collected from the household survey would benefit the overall programming.

A total of 862 children with disability were reached in 839 households. This suggests that some households had more than one child aged 2-17 years with a disability. Of these children, 128 were aged between 2-4 years while 734 fell in the age category of 5-17 years. Of the children with disability (n=379,44.0%) were boys while (n=483,56.0%) were girls. More than a third of the children (n=327,37.9%) were in Kakuma ward, while Songot ward had the least number of children (n=53,6.1%). While this study attempted to survey the entire population of children with disability, there are likely more children with disability and more households in Turkana West Sub-County with children with disability than those enumerated. The project data estimates that there were approximately 900 children with disability, which closely mirrors the number surveyed. This number should therefore be treated as a fairly good estimate of children with disability in the subcounty, as opposed to an accurate full census.

The 2019 Kenya Population and Housing Census<sup>23</sup> data only gives the total number of people aged 5 years and more with disability in Turkana West Sub County. The data shows that a total of 2,395 persons, 1,227 male and 1,168 female had disability. This translates to about 1.2% of the sub-county population. According to the data mobility difficulties were the most common followed by sight difficulties. The two were followed by cognition, self-care, communication, and hearing difficulties in that order. This data is at best indicative.

In line with the CFM, different aspects of functionality were explored as discussed below.

#### 3.1.1 Sight

Findings show that while more than a third (n=227,32.6%) of children with disability aged 5-17 years had difficulties seeing, a lot of difficulty, (n=89,39.2%), (cannot see at all, n=26,11.5%), and

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<sup>23</sup> Kenya National Bureau of Statistics (2019): Distribution of Population by Social Economic Characteristics. Volume IV

(some difficulty, n=112,49.3%), a minority (n=37,5%) wore glasses or contact lenses. The proportion of girls with disability, who had difficulty seeing was 31.1% while that of boys was 34.4%. More than two-thirds of children in this age category (n=470,67.4%) did not have difficulties seeing. The findings were mirrored among children aged 2-4 years. While (n=40,31.7%) have difficulties seeing, (n=13,32.5%), have a lot of difficulty, (n=24,60%) have some difficulty, and (n=3,7.5%), cannot see at all. However, very few (n=2,1.6%) of children in this age category wore glasses. More than a third of boys with a disability, 36.1%, aged 2-4 years, and a quarter of girls, 25.9% had difficulties seeing. This could imply that access to glasses and contact lenses was limited, despite the larger number of children in need. Yet, more than half of those with glasses or contact lenses reported that they did not experience any difficulty seeing, which points to the ability of these devices to improve the children's ability to see<sup>24</sup>. More than two-thirds (n=86,68.3%) do not have difficulties seeing.

Across wards, Songot had the highest proportion of children, 5-17 years with seeing difficulties (n=30,65%), while Nanaam had the least proportion (n=15,20%). Similarly, Songot ward had the highest proportion of children 2-4 years old with difficulties seeing, while Nanaam ward had the least. Besides, experiencing delays in their language, emotional, cognitive, and social development<sup>25</sup>, children experiencing sight difficulties may also experience low education attainment, low literacy, and low school completion rates compared to children without this disability<sup>26</sup>. These findings were echoed in an interview with a psychosocial specialist.

### 3.1.2 Hearing

Findings on hearing difficulties show that more than a third (n=244, 35.8%) of children with disabilities aged 5-17 years, experience difficulties hearing sounds like people's voices and music. The proportion of boys with hearing difficulties was 34.8% while that of girls was 36.9%. However, only (n=52,7.1%) of the children in this age category use a hearing aid. Furthermore, even when using one, a majority (n=41,78.9%) still experienced difficulties hearing people's voices and music. This finding suggests that the few hearing aids accessible to children aged 5-17 years may not be functional. Songot ward had the highest proportion of children 5-17 years experiencing hearing difficulties (n=27,58.7%), while Nanaam ward had the lowest proportion (n=19,24.7%).

Similarly, about a third (n=39,32.5%) of children aged 2-4 years had difficulties hearing sounds like people's voices and music. The proportion of boys with this difficulty was 39.4% and that of girls was 22.4%. However, only (n=8,6.3%) of children in this age group used a hearing aid, with half of them reporting that even with the hearing aids they still experienced difficulties hearing. For children aged 2-4 years, Lopur ward had the highest proportion of children with hearing difficulties (n=12,57.1%) while Nanaam had the lowest proportion (n=1,9.1%). Reports note that difficulties in hearing may cause delayed language and speech skills, which can affect their social interactions, learning, and communication<sup>27</sup>. Besides affecting the children's literacy, education attainment, and school completion ability, hearing difficulties may also lead to low self-esteem and social isolation. The situation is further complicated by limited access to hearing care services across the sub-county<sup>28</sup>.

<sup>24</sup> <https://www.iapb.org/learn/vision-atlas/magnitude-and-projections/child-eye-health/>

<sup>25</sup> <https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment>

<sup>26</sup> <https://www.iapb.org/news/children-with-visual-impairment-lag-behind-in-school-and-learning-a-study/>

<sup>27</sup> <https://www.asha.org/public/hearing/Effects-of-Hearing-Loss-on-Development/>

<sup>28</sup> <https://www.asha.org/public/hearing/Effects-of-Hearing-Loss-on-Development/>

### 3.1.3 Walking

Concerning walking, (n=85,11.6%) of children aged 5-17 years use equipment or receive assistance, without which, all face difficulties walking 100 yards (91.4 meters) on level ground. Girls with this difficulty were reported to be approximately 9.5% while boys were approximately 13%. When using their equipment or with assistance, close to a third of children aged 5-17 years (n=23,27.1%) have no difficulty walking 100 yards (91.4 meters). This suggests that two-thirds of the children still face a lot of difficulty (n=20,23.5%), or some difficulty (n=39,45.9%) or they would not be able to walk at all (n=3,3.5%). For those reporting that they faced difficulty walking 100 yards or (91.4 meters), a majority, (n=25, 96.2%), faced a lot of difficulty, (n=5,19.2%) or some difficulty (n=20,76.9%) walking 500 yards (457.2 meters) on level ground without their equipment of assistance. However, with their equipment or assistance, (n=20,32.3%) faced no difficulty walking 500 yards (457.2 meters), (n=35,56.5%) faced some difficulty, and (n=6,9.7%) faced a lot of difficulty.

When asked to compare with other children of the same age, findings show that about a third (n=211,32.5%) of children with disability aged 5-17 years faced difficulties walking a distance of 100 yards (91.4 meters). Of these, (n=81,38.4%) faced a lot of difficulty, (n=113,53.6%) faced some difficulty, and (n=17, 8.1%) could not walk a distance of 100 yards at all. Overall, just about a quarter of children, living with disability, and aged 5-17 years (n=147,26.8%) faced difficulties walking 500 yards (457.2 metres) on level ground compared with children of the same age.

Findings related to walking for children with disability aged 2-4 years show that (n=18,14.1%) used equipment or received assistance to walk. The proportion of girls with this difficulty for this age category stood at 12.9% while that of boys stood at 14.9%. There were comparatively more children with walking difficulties in Nanaam ward compared to the other wards. A majority (n=110,85.9%) do not use any equipment or assistance. For those in need of assistance or support to walk, (n=9,50%) face a lot of difficulty, (n=4,22.2%) face some difficulty and a few more (n=2,11.4%) cannot walk at all. However, even when using equipment or with support, (n=12,66.8%) still faced difficulties walking which implies that the equipment they used or the support they received did not quite effectively resolve their walking difficulties. When asked to compare the children's walking capability with that of other children, close to half of the children (n=52,46.8%) were reported to experience more difficulty walking.

Walking difficulties not only affect children's participation in sports and recreation both of which may affect their health fitness and social skills, but it also poses challenges such as effective participation in school and community events, which affects their learning engagements and even inclusion<sup>29</sup>. Interviews with key informants further noted the environmental barriers that complicate matters for children with walking disabilities. Besides the poor road and transport network, physical access to schools, health facilities, and social services remains a challenge. One key informant for example noted'

*'There are caregivers who have to carry their children to school on their backs. This becomes more and more difficult as the child gets older and becomes heavier. KII Kakuma*

Others noted that some organisations such as Humanity and Inclusion, NCPWD, and WKP among others supported children with assistive devices such as clutches and wheelchairs, but many children were yet to access them.

<sup>29</sup> <https://www.washington.edu/doit/mobility-impairments>



Photo courtesy: WKP: Child after they received a wheelchair

### 3.1.4 Picking up small objects with hands

This aspect is relevant in assessing children aged 2-4 years. When compared with other children of the same age, more than half of the children with disability (n=68,53.1%) experienced difficulties picking up small objects with their hands. Of these, (n=25,36.8%) faced a lot of difficulty, (n=40,58.8%) faced some difficulty, while a few (n=3, 4.4%) could not pick small objects with their hands at all. More than half of the girls with disability, 55.6% as well as boys, 51.4% experienced difficulty picking up small objects with their hands. Kakuma ward had a comparatively larger proportion of children with difficulties picking small objects with their hands (n=39,63.9%), followed by Lopur (13, 56.5%), while Kalobeyei had the lowest proportion.

In younger children, difficulties in picking up small objects with their hands could suggest delayed fine motor skills, which can affect their manipulation, dexterity, and eye-hand coordination. In older children, this may result in difficulty performing daily activities, such as dressing, eating, writing, or using tools, which can affect their independence, self-care, and productivity<sup>30</sup>. This underscores the need to ensure that children with difficulty picking up small objects with their hands have timely access to quality health care, inclusive education, and supportive family and community environments. In addition, occupational therapy, physical therapy, or orthotic devices are essential to improving their strength, range of motion, or alignment.<sup>31</sup> Furthermore, the provision of appropriate and customized assistive devices, such as adapted utensils, writing tools, or toys, that

<sup>30</sup> <https://www.psychologytoday.com/us/blog/coaching-and-parenting-young-athletes/202203/the-effects-motor-impairment-may-have-children>

<sup>31</sup> [https://link.springer.com/referenceworkentry/10.1007/978-1-4419-1698-3\\_619](https://link.springer.com/referenceworkentry/10.1007/978-1-4419-1698-3_619)

can improve their functionality and satisfaction would help to mitigate the challenges such children faced<sup>32</sup>

The key informants suggested that such children may be provided with different play materials and toys that encourage them to use their fingers and hands, such as small stone blocks, puzzles, clay, beads, or buttons. They could also be encouraged to play games and activities that involve picking, pinching, squeezing, or grasping objects, such as sorting, matching, threading, or popping bubbles. Moreover, the children could be encouraged to use both hands together, such as clapping, rolling, or cutting with scissors.

### 3.1.5 Understanding the caregiver

Each caregiver was asked if their child had any difficulties understanding them. Close to half (n=59,46.1%) reported that their children aged 2-4 years and with disability had difficulties understanding them. Of these (n=18,30.5%) have a lot of difficulty, (n=39,66.1%) have some difficulty while a few (n=2,3.4%) cannot understand the caregiver at all. This was the case for approximately 50% of boys and 40.7% of girls with disability. This suggests that close to half of children aged 2-4 years and with a disability might already have challenges developing their intellectual and mental faculties. More than half of caregivers in Lokichogio, Lopur, and Kakuma wards said their children had difficulties understanding them. In the same light, close to half of caregivers (n=63,49.2%) said that they face difficulties understanding their children aged 2-4 years when they speak. Among these, (n=19,30.2%) face a lot of difficulty, (n=34,54%) face some difficulty and (n=10,15.8%) cannot understand their child at all when they speak. This was reported by more than half of caregivers in Lokichogio, Lopur, and Nanaam and almost half in Kakuma. This difficulty affected approximately 51.4% of boys and 46.3% of girls with disability. Just about half (n=65,51%) do not have any difficulties.

Reports by experts indicate that difficulties by a child in understanding the caregiver may lead to poor attachment and bonding with the caregiver, which can affect their emotional security and trust<sup>33</sup>. Reports further indicate that children facing such difficulties may have reduced social and communication skills, which can affect their interactions and relationships with others, and may also lower their confidence and self-esteem<sup>34</sup>. The challenge may also lead to difficulty following instructions and routines, which can affect their learning and behaviour, and increased stress and anxiety, which can affect their mental health and well-being. Experts suggest that children facing such difficulty would need speech and language therapy, which can improve their receptive and expressive language skills<sup>35</sup>, hearing screening and treatment, which can rule out or inform the approach in addressing any hearing problems that may affect their language comprehension<sup>36</sup>, while parent training and support, can equip caregivers with strategies that can aid effective communication with their children<sup>37</sup>.

### 3.1.6 Learning Abilities

On learning abilities, close to half of children with disability aged 5-17 years (n=330,45%) have difficulty learning things. Of these (n=203,6.5%) have some difficulty, (n=109,33%) have a lot of difficulty, and (n=18,5.5%) cannot learn things at all. However, more than half of children with disability aged 5-17 years (n=404,55%) do not face difficulties learning things. This difficulty affected approximately 46.5% of girls and 43.8% of boys with disability. The highest proportion was reported in Lopur (n=74,63.2%) and Kakuma wards (n=161,60.5%). The lowest proportion

<sup>32</sup> <https://thewarrencenter.org/help-information/fine-motor/what-are-fine-motor-developmental-delays/>

<sup>33</sup> <https://www.stanfordchildrens.org/en/topic/default?id=communication-disorders-90-P02559>

<sup>34</sup> <https://www.cdc.gov/ncbddd/developmentaldisabilities/language-disorders.html>

<sup>35</sup> <https://www.icphs2019.org/the-impact-of-speech-and-language-disorders-on-communication-and-learning>

<sup>36</sup> <https://www.cdc.gov/ncbddd/developmentaldisabilities/language-disorders.html>

<sup>37</sup> <https://www.cdc.gov/ncbddd/developmentaldisabilities/language-disorders.html>

was recorded in Lokichogio ward (n=21,18.6%). Moreover, more than half the children aged 2-4 years and with disability (n=74,57.8%) experienced difficulty learning things compared with children of the same age, as reported by caregivers. Findings show that (n=45,60.8%) face some difficulty, (n=24,32.4%) face a lot of difficulties, and (n=5,6.8%) cannot learn at all. A significant (n=54,42.1%) have no difficulty learning things compared to children of the same age. This difficulty affected proportionately more boys, 64.9% compared to 48.1% of girls with disability. Kakuma ward registered the highest proportion of children in this age category with difficulties learning things (n=41,67.2%), followed by Nanaam and Songot wards (66.7% respectively).

Difficulties in learning abilities could lead to lower levels of academic achievement, literacy, and school completion. Children with such difficulties may experience low self-esteem, confidence, and motivation, which can affect their resilience and aspirations<sup>38</sup>. They may also have reduced social and emotional skills, which can affect their interactions and relationships with others, besides encountering attitudinal barriers, such as stigma, discrimination, or low expectations, which can affect their opportunities and outcomes<sup>39</sup>. Such children with learning difficulties may benefit from assessment and diagnosis of their specific learning needs and strengths, inclusion and participation in school and community activities, with peer and adult support, and awareness and advocacy for the rights and needs of children with disabilities who have difficulties learning things<sup>40 41</sup>

### 3.1.7 Remembering Abilities

This assessment aspect is relevant to children aged 5-17 years. From the findings, more than a third of children (n=285, 38.8%) have difficulty remembering things. More than two-thirds of them (n=184,64.6%) have some difficulty, a quarter (n=78,27.4%) have a lot of difficulty, while (n=23, 8.1%) cannot remember at all. More than half (n=449,61.2%) have no difficulty remembering things. Approximately 41% of girls and 37% of boys with a disability experienced difficulty remembering things. Lopur ward had the highest proportion of children with this difficulty (n=60,51.3%) followed by Kakuma ward where (n=127,47.7%) of children 5-17 years experienced this difficulty. Nanaam ward had the least proportion (n=20,22.5%).

Reports note that difficulties remembering things may lead to poor academic performance, as memory is essential for learning new information, recalling facts, and solving problems<sup>42</sup>. Such children may also have trouble forming and maintaining relationships, as memory supports social skills, such as recognizing faces, names, emotions, and conversational cues. It may also result in low self-esteem, confidence, and motivation, as memory affects their sense of identity, continuity, and achievement<sup>43</sup>.

Besides, early assessment and diagnosis, the provision of appropriate, customized, and contextualized memory aids, such as calendars, notebooks, or alarms, and the use of shadows that can improve their recall and functionality could help. Experts further recommend inclusion and participation in school and community activities, with appropriate accommodations and adaptations, such as repetition, cues, or feedback, in addition to awareness and advocacy for the rights and needs of children with disabilities who have difficulties remembering things.

<sup>38</sup> <https://www.verywellfamily.com/how-learning-disabilities-can-affect-behavior-2161916>

<sup>39</sup> <https://www.mayoclinic.org/healthy-lifestyle/childrens-health/in-depth/learning-disorders/art-20046105>

<sup>40</sup> <https://www.verywellfamily.com/how-learning-disabilities-can-affect-behavior-2161916>

<sup>41</sup> <https://www.worldbank.org/en/news/press-release/2017/12/01/children-with-disabilities-are-being-left-behind>

<sup>42</sup> <https://www.thinkkids.com/blog/what-causes-memory-problems-in-children>

<sup>43</sup> <https://www.idaminnnesota.org/community-programs/fact-sheets/can-memory-problems-cause-learning-disability/>

### 3.1.8 Concentration

More than a third of children with disability aged 5-17 years (n=262,35.9%) have difficulty concentrating on an activity that they enjoy doing. Among these, (n=176,67.1%) have some difficulty, (n=75,28.6%) have a lot of difficulty, and (n=11,4.2%) cannot concentrate at all. Approximately 35% of boys and 37% of girls with a disability experienced difficulty concentrating. Lopur ward had the highest proportion of children experiencing this difficulty (n=64,54.7%) followed by Kakuma (n=121,45.5%). The lowest proportion was recorded in Lokichogio (n=13,11.5%) More than half, however (n=472,64.3%) have no difficulty concentrating on an activity they enjoy doing.

Difficulty in concentrating may lead to problems in following instructions, completing tasks, or organizing their time, which can affect their independence, self-care, and productivity, and cause clumsy behaviour<sup>44</sup>. Experts recommend some practical lifestyle strategies to improve concentration which include, getting enough sleep; eating a balanced diet, remaining hydrated, and increasing physical activity<sup>45</sup>. According to the Center for Disease Control and Prevention (CDC),<sup>46</sup> the recommended hours of sleep per day by age are as below.

- New-borns aged 0-3 months require 14-17 hours of sleep per day
- Infants aged 4-12 months require 12-16 hours per 24 hours (including naps)
- Toddlers aged 1–2 years require 11–14 hours per 24 hours (including naps)
- Pre-school children aged 3–5 years require 10–13 hours per 24 hours (including naps)
- School-age children aged 6–12 years require 9–12 hours per 24 hours
- Teenagers aged 13–18 years require 8–10 hours per 24 hours
- Adults aged 18 years and above require 7-8 or more hours of sleep per night

### 3.1.9 Accepting change in routine

More than a third of children with disability aged 5-17 years (n=249,33.9%) have difficulty accepting change in their routine. Among them (n=64,25.7%) have a lot of difficulty, (n=174,69.9%) have some difficulty while another (n=11,4.4%) cannot accept change in routine at all. This was the case for approximately 34.2% of boys and 33.5% of girls with disability. Lopur ward had a higher proportion of children facing this difficulty followed by Kakuma with (n=108,40.6%). The lowest proportion was recorded in Lokichogio (n=10,8.8%). However, more than half of the children (n=485,66.1%) do not have difficulty accepting a change in routine.

Reports show that children who have difficulties in accepting change in routine may experience more stress, anxiety, frustration, and confusion when faced with unfamiliar or unpredictable situations. This can impair their cognitive, emotional, social, and physical development, as well as their academic performance and achievement<sup>47</sup>. Discussions with key informants further indicated that children who have difficulties accepting routine may also exhibit more negative behaviours, such as tantrums, aggression, self-injury, or withdrawal when they encounter changes that they perceive as threatening or challenging.

*'They may also develop more emotional problems, such as depression, low self-esteem, or fear, that can affect their well-being and quality of life'. KII with psychosocial specialist*

<sup>44</sup> <https://mentallyhealthyschools.org.uk/mental-health-needs/overactivity-and-poor-concentration/>

<sup>45</sup> <https://www.medicalnewstoday.com/articles/unable-to-concentrate#home-remedies>

<sup>46</sup> [https://www.cdc.gov/sleep/about\\_sleep/how\\_much\\_sleep.html](https://www.cdc.gov/sleep/about_sleep/how_much_sleep.html)

<sup>47</sup> <https://www.caudwellchildren.com/setting-a-routine-for-disabled-children/>

### 3.1.10 Controlling own behaviour

Just about a third of children with disability aged 5-17 years (n=240,32.7%) have difficulty controlling their behaviour. Among them, (n=67,27.9%) have a lot of difficulty, (n=162, 67.5%), have some difficulty, and (n=11,4.6%) cannot control their behaviour at all. This difficulty was experienced by about 34.5% of girls and 31.3% of boys with disability. Lopur ward had a higher proportion of children with this difficulty (n=62,53%) followed by Kakuma ward (n=102,38.3%). The lowest proportion was in Lokichogio ward (n=13,11.5%). Findings show that more than half of the children (n=494,67.3%) have no difficulty controlling their behaviour. According to the Center for Disease Control (CDC), children sometimes argue, are aggressive, or act angry or defiant around adults. A behaviour disorder may be diagnosed when these disruptive behaviours are uncommon for the child's age at the time, persist over time, or are severe.

Because disruptive behaviour disorders involve acting out and showing unwanted behaviour towards others, they are sometimes called externalizing disorders<sup>48</sup>. CDC further notes that one way to mitigate such difficulties in managing their behaviour could include training parents on effective ways to strengthen the parent-child relationship and respond to the child's behaviour. For school-age children and teens, another often-used effective treatment is a combination of training and therapy that includes the child, the family, and the school.

### 3.1.11 Making friends

Close to half of children with disability aged 5-17 years (n=209,47%) have difficulty making friends. Among them (n=138,66%) have some difficulty, (n=53,25.4%) have a lot of difficulty, and (n=18,8.6%) cannot make friends. This difficulty affected proportionately more girls, 30.2% compared to 27.1% of boys with disability. Lopur ward had the highest proportion (n=58,49.6%) of children experiencing this difficulty according to caregivers, followed by Letea ward with (n=14,31.1%). A majority of the children (n=525, 71.5%), however, do not have difficulty making friends.

Reports indicate that friendships need nurturing, in a similar way to more intimate relationships. Sometimes parents fail to prioritize friendships because they feel that family can provide all the social connections the child needs, possibly fearing that exposure to a wider social network will open the door to abuse. Although most parents are concerned about how their children will manage without them in the future, they don't regard friendships as a key component of their children's support<sup>49</sup>. To help children counter this difficulty, experts advise that it is important for parents to take a keen interest in the things their children like to do. Additionally, parents can help by having a family game time where children practice social skills that are important for friendships, but that are often lacking in children with friendship difficulties. Some examples of these skills are good sportsmanship, turn-taking, staying calm when things don't go your way, finishing the activities you start, and following game rules among others<sup>50</sup>.

### 3.1.12 Seeming very anxious, nervous, and worried

Close to two-thirds of children with disability aged 5-17 years (n=460,62.7%) often seem very anxious, nervous, and worried. This happens a few times a year for (n=93,20.2%), daily for (n=150,32.6%), monthly for (n=70,15.2%) and weekly for (n=147,32%). No major differences were seen across genders, even though this difficulty was experienced by approximately two-thirds of children with disabilities. More than a third of children (n=274,37.3%), did not frequently seem very anxious, nervous, and worried. Experts note that anxiety is a natural reaction to challenging situations<sup>51</sup>. Children with disability or chronic conditions are more likely than other children to

<sup>48</sup> <https://www.cdc.gov/childrensmentalhealth/behavior.html>

<sup>49</sup> <https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving/supported-loving-toolkit/making-friends>

<sup>50</sup> <https://chadd.org/adhd-news/adhd-news-caregivers/friendship-problems-how-parents-can-help/>

<sup>51</sup> <https://raisingchildren.net.au/disability/mental-health-physical-health/anxiety/anxiety-children-with-disability>

experience anxiety. This is because their disability or condition is unpredictable or significantly affects their daily lives. They are more likely to experience bullying, they feel different from their peers, they have learning difficulties, intellectual disability, or difficulties with social understanding that make it harder for them to understand what's happening around them<sup>52</sup>. Reports recommend that parents or caregivers of children facing anxiety should acknowledge their child's fear, gently encouraging their child to do things they feel anxious about and praising their children when they try to face their fears<sup>53</sup>.

### 3.1.13 Seeming very sad and depressed

The study further explored from caregivers the extent to which children with disability aged 5-17 years seemed very sad and depressed. While more than a third (n=273,37.2%) did not often seem very sad and depressed, more than half of them (n=461,62.8%) often seemed very sad and depressed. Among them (n=91,19.7%) seemed very sad and depressed a few times a year, (n=120,26%) seemed very sad and depressed daily, (n=86,18.7%) seemed very sad and depressed monthly, while (n=164,35.6%) seemed sad and depressed weekly. This finding was mirrored in the proportion of girls and boys with disability reported to be experiencing this difficulty. Similarly, caregivers in Kalobeyei ward recorded the highest proportion of children experiencing this difficulty (n=53,98.1%), followed by Lopur ward (n=100,85.5%), and Kakuma ward (n=224,84.2%). Reports indicate that children with disability or chronic conditions are more likely to experience low mood and depression than their peers. This is because children with disability or chronic conditions might, often be in pain, feel different from their peers, feel that their condition gets in the way of daily life, experience bullying, struggle with school work, or experience painful medical procedures<sup>54</sup>.

Experts further note that there are many practical things that caregivers of children with disability can do to support them through depression. These include, managing the child's stress and making time for talking, helping the child think beyond their health, what they are good at, where they can succeed, and what's important to them. Additionally, it is good to develop a plan that helps your child keep up with school work and friends, support the child's friendships and activities, and help them find ways to make and maintain new relationships. Parents can also encourage their children to tell trusted friends about their disability or condition. This can strengthen their friendships and help them feel more supported. They could also help their children to work out what soothes them or help them cope. For example, they might like to be hugged or play with a toy they like. Most importantly they note that it is important to let their children know that it is okay to be angry or frustrated and encourage them to be kind to themselves when they feel this way<sup>55</sup>.

### 3.1.14 Playing

More than half of children aged 2-4 years (n=74,57.8%) have difficulties playing compared to children of the same age. Among these (n=44,59.5%) have some difficulty, (n=24,32.4%) have a lot of difficulties, and (n=6,8.1%) cannot play. Across genders, 55.4% of boys and 61.1% of girls with disability also experienced difficulties playing. Kakuma ward had the highest proportion of caregivers (n=44,72.1%) reporting that their children experienced difficulty playing followed by Nanaam ward (n=7,58.3%). The lowest proportion was in Kalobeyei as reported by (n=1,16.7%) of caregivers. However, (n=54,42.1%) do not have difficulty playing compared to children of the same age. The inability to play may inhibit children's ability to learn and develop. Given that their inability to play may be a result of physical limitations, and sensory, cognitive, communication,

<sup>52</sup> <https://raisingchildren.net.au/disability/mental-health-physical-health/anxiety/anxiety-children-with-disability>

<sup>53</sup> <https://raisingchildren.net.au/disability/mental-health-physical-health/anxiety/anxiety-children-with-disability>

<sup>54</sup> <https://raisingchildren.net.au/disability/mental-health-physical-health/depression/depression-children-with-disability>

<sup>55</sup> <https://raisingchildren.net.au/disability/mental-health-physical-health/depression/depression-children-with-disability>

emotional, and behavioural impairments, children with disabilities must be provided with play opportunities and resources that suit their abilities, interests, and preferences. This may include a variety of toys, and accessible materials, the creation of safe and comfortable play environments, teaching them to play including skills and strategies on the use of toys, and praising and rewarding their play efforts among others. UNICEF<sup>56</sup> notes that one of the best ways for children to learn, no matter their abilities, is through play. Play is all about discovery and having fun. A parent or caregiver should nevertheless be patient, listen, and enjoy spending time and learning together with their child.

UNICEF shares ideas of stimulating activities that caregivers can do with their children. These include placing a variety of toys such as sponges and cups on a flat surface to stimulate the child, making up a game using a homemade ball made of cloth, and making a video of the things caregivers have recorded their child doing and playing it for them. One can also do this with just an audio recorder to play back their singing or laughing. Caregivers can also take their children to the kitchen to help prepare food. Depending on what they are doing and how interested the child is, they can let them help out or just give them their plastic bowl and spoon to mimic their actions, and sing, dance, and make noise with the child. Children can use any cooking pot and homemade instruments to keep rhythm with the caregivers.

### **3.1.15 Kick, bite, or hit other children**

While half of the children aged 2-4 years and with disability (n=64,50%) did not kick, bite, or hit other children more than other children of the same age, a small number (n=9,7%) did. The findings further show that (n=56,43.8%) kick, bite, or hit other children the same or less, compared to other children of the same age. Slightly more girls 48.2% compared to 40.5% of boys with a disability kick, bite, or hit other children the same or less compared to other children their age. There were no fundamental differences across the wards. This suggests that children with disability aged 2-4 years in Turkana West Sub County exhibit normal physical aggression, which is a normal way of expressing anger, frustrations, or fear for such children who may have limited language skills.

### **3.1.16 Self-care such as feeding and dressing**

This assessment aspect was relevant for children with disability aged 5-17 years. Overall, more than a third of the children (n=291,39.6%), have difficulties with self-care, including dressing and feeding. Among them (n=79,27.1%) have a lot of difficulty, (n=196,67.4%) have some difficulty while another (n=16,5.5%) cannot do it at all. Proportionately, more boys, 40.6% compared to 38.5% of girls with a disability experienced this difficulty. More than half the caregivers in Songot (n=26,52%) reported that their children faced this difficulty. The same was reported by (n=128,48.1%) in Kakuma and (n=21,46.7%) in Letea ward.

### **3.1.17 Difficulty being understood inside the household**

Findings show that (n=296,40.3%) have difficulty being understood when they speak in their household. This affected proportionately 42.3% of boys and 37.8% of girls with disability. Of these (n=85,28.7%) have a lot of difficulty being understood, (n=185,62.5%) have some difficulty and (n=26,8.8%) cannot be understood at all. This was reported by more than half of the caregivers in Kakuma (n=135,50.8%) and by (n=11,20.4%) in Kalobeyei ward. More than half, however (n=438,59.7%) did not have difficulties being understood inside their households. In comparison, (n=315,42.9%), have difficulties being understood when they speak outside their households. Among these, (n=99,31.2%) face a lot of difficulties, (n=186,59%) face some difficulties, and (n=30,9.5%) cannot be understood at all. This was reported by (n=66,56.4%) of caregivers in Lopur ward, and by (n=138, 51.9%) in Kakuma.

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<sup>56</sup> <https://www.unicef.org/parenting/child-care/10-playful-educational-activities-children-disabilities>

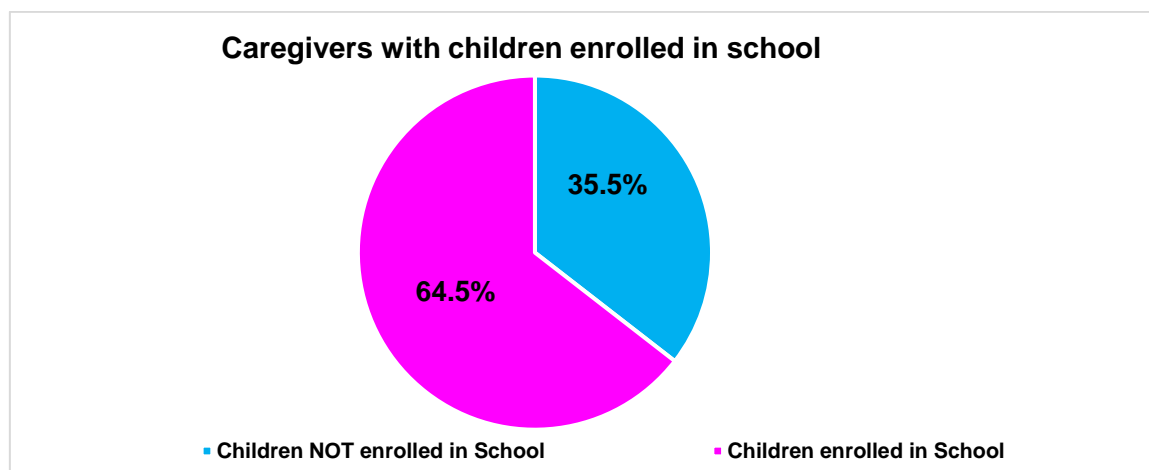
### 3.1.18 Albinism

None of the children with a disability aged 2-4 years were reported to have albinism, compared to four children aged 5-17 years with albinism. Of those with albinism, three (3) were in Kakuma Ward and one (1) in Lopur ward. One was a girl and 3 were boys.

### 3.2 Education situation of children with disabilities

#### *Enrolment and access to learning facilities*

More than two-thirds of caregivers of children with disabilities (n=556, 64.5%) reported that their children were enrolled in school at the time of this study. Slightly over one-third (n=306, 35.5%) were not in school as seen below.



**Figure 3: Children enrolled in school**

This finding was mirrored across genders. It was also noted that at least about half of children with disability were enrolled in schools except in Letea ward where just about a third (n=17,29.8%) of children with disability were enrolled in schools. This is seen in the table below.

**Table 1: School Enrolment by Ward**

Is your CHILD currently enrolled in school?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
No	127	8	40	16	62	26	27	306
	38.8%	13.3%	70.2%	12.9%	44.3%	25.7%	50.9%	35.5%
Yes	200	52	17	108	78	75	26	556
	61.2%	86.7%	29.8%	87.1%	55.7%	74.3%	49.1%	64.5%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

Of the children reported to be in school, (n=529, 95.2%) were in ordinary schools, and a small number (n=27, 4.9%) were in special schools. Discussions with stakeholders indicated that there was only one school with special facilities and staff with specialized skills in the sub-county. More than half of children with disabilities and in school (n=314, 56.4%) were at the primary school level, while slightly more than a third (n=200, 36%) were in pre-school. A few (n=26, 4.7%) were in secondary schools. A small number were in tertiary/college, while a few parents/caregivers (n=14,2.5%) did not know the level of education their children were in.

A majority of the children with disabilities in school (n=538,96.8%) attended general classrooms with other children without disabilities, suggesting an inevitable process toward integrated learning, possibly forced by a lack of alternative learning facilities. It is important to note that global trends now advocate for integrated learning, an approach that the government policy and programming efforts by non-governmental organizations are encouraging. However, discussions with some teachers seemed to be in favour of special schools. They gave an example of the Kainuk school for the blind, where they argued that children enrolled in the school performed better and ended up doing much better in life. This was largely due to the availability of relevant and special needs facilities and trained staff.

Caregivers of children with disabilities were asked if educational institutions were available for their children, to which a majority (n=345, 84.6%), said no. Only (n=63,15.4%) said that educational institutions were available for children with disabilities. A majority of those reporting that institutions were available said that the institutions were ordinary schools. Slightly more than a third (n=149,36.5%) of these caregivers did not know to what grade children with disabilities were able to attend formal education. A few (n=47,11.5%) said only pre-school was available while (n=90,22.1%) said formal education was available up to the tertiary or college levels.

According to close to half of caregivers of children without disabilities, (n=353,41.5%), failure by the government to establish institutions was the reason for the few learning institutions in Turkana West Sub County. Others believed that no NGO or CBO had established a school (n=172, 20.2%), that it was costly to establish a school for children with disabilities (n=97,11.4%), that children with disabilities were not many in the community (n=80,9.4%), and that there was no need for a school for children with disability as reported by (n=68, 8%).

Community members interviewed in FGDs observed that part of the challenge was that community members did not value education. This was the reason why schools were few and always registering low levels of enrolment. A community member in an FGD noted,  
*"Here in Turkana people do not value education at all and this translates to the limited educational facilities we have in our county, personally, in our village we only have a primary school which has few students and we do not have a secondary school anywhere close"*

In another FGD, community members reported that most parents with children with disabilities take them to school not necessarily to learn, but for other benefits derived from school such as a free meal, the possibility of being identified for support by a donor, or the possibility that their children will be more protected in the school environment than at home.

#### *School ownership*

A majority of the schools accessible to children with disabilities in Turkana West Sub County were either county or national government-owned as reported by (n=693,80.4%) of caregivers of children with disabilities. Others were owned by Non-Governmental Organisations (NGOs) (n=96,11.1%), Faith-Based Organizations (FBOs) (n=31,3.6%), and international agencies (n=20,2.3%). This finding mirrored findings from caregivers of children without disabilities, a majority of whom (n=327,80.2%) reported that schools were owned by the government (national and county). Others reported NGOs (68,16.7%), and FBOs (n=9,2.2%).

#### *Teacher and caregiver communication*

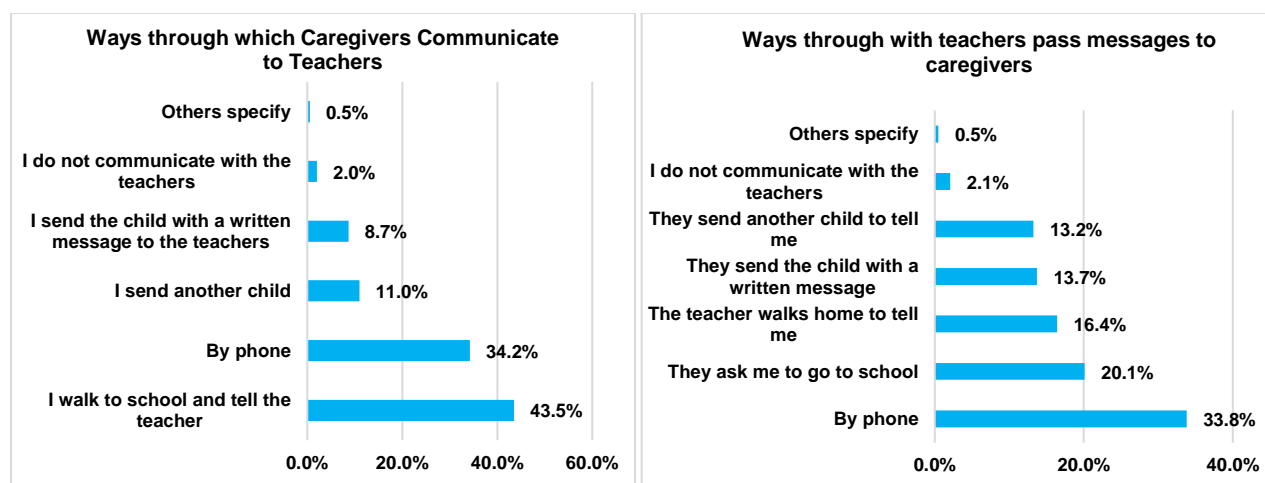
Consistent communication between teachers and caregivers ensures that gaps in monitoring the progress and care of children with disabilities in schools and at home are minimized. This study, therefore, sought to understand ways in which caregivers communicated with teachers. Close to half (n=326,43.6%) indicated that they walked to school if they needed to pass any information to

the teachers. Slightly more than a third (n=256, 34.2%) use their phones, while another (n=82,11%) send another child. Other caregivers (n=65,8.7%) send the child with a written note to the teachers. A few caregivers (n=15,2%) did not communicate with the teachers. This is seen in the table below.

**Table 2: How parents/caregivers communicate with teachers by ward**

How do you communicate with the teacher if Your CHILD requires specific attention								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
By phone	91	18	8	34	27	62	16	256
	36.9%	19.2%	22.9%	27.6%	24.1%	74.7%	29.1%	34.2%
I send the child with a written message to the teachers	18	3	4	6	24	1	9	65
	7.3%	3.2%	11.4%	4.9%	21.4%	1.2%	16.4%	8.7%
I walk to school and tell the teacher	110	47	16	69	46	19	19	326
	44.7%	50.0%	45.7%	56.1%	41.1%	22.9%	34.6%	43.6%
I send another child	16	25	7	13	11	1	9	82
	6.5%	26.6%	20.0%	10.6%	9.8%	1.2%	16.4%	10.9%
I do not communicate with the teachers	10	0	0	0	3	0	2	15
	4.1%	0.0%	0.0%	0.0%	2.7%	0.0%	3.6%	2.0%
Others specify	1	1	0	1	1	0	0	4
	0.4%	1.1%	0.0%	0.8%	0.9%	0.0%	0.0%	0.5%
<b>Total</b>	<b>246</b>	<b>94</b>	<b>35</b>	<b>123</b>	<b>112</b>	<b>83</b>	<b>55</b>	<b>748</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

For communication triggered by the teachers, about a third of caregivers (n=276,33.8%) reported that teachers communicate to them by phone which mirrors caregivers reporting that they communicate to teachers on the phone. Another (n=164,20.1%) said that teachers call them to school, while (n=135,16.5%) reported that teachers walk to their homes to inform them of any updates. Some caregivers (n=112,13.7%) reported that teachers send the child with a written message. These findings are seen below.



**Figure 4: Ways teachers and caregivers communicate about the child**

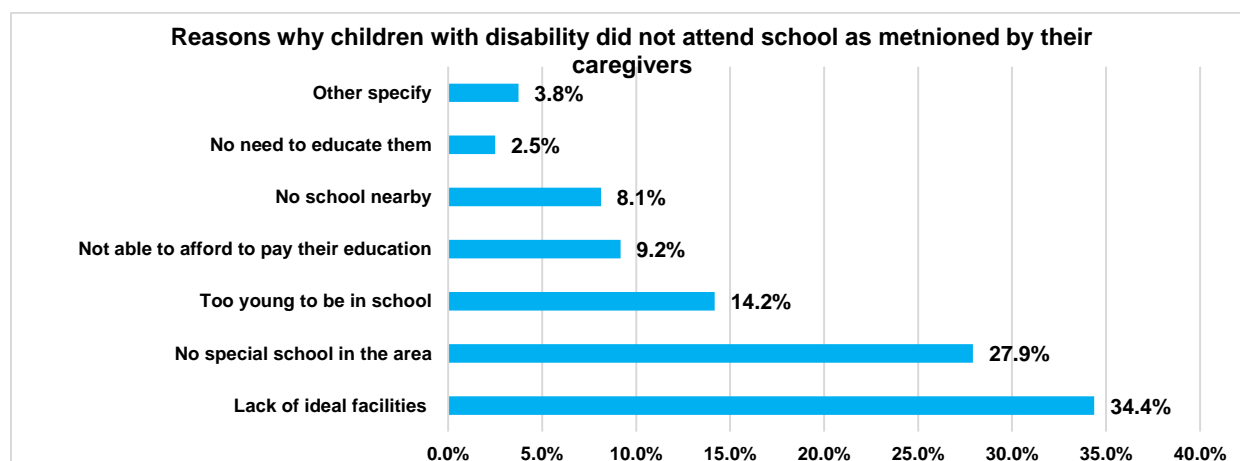
Children with disability and NOT in school

Close to a third of caregivers (n=238,28.4%) were aware of other children with disabilities not attending school. There were proportionately more caregivers in Songot Ward compared to other wards who were aware of children with disability who were not attending school as seen in the table below.

**Table 3: Caregivers aware of other children with disability not attending school by ward**

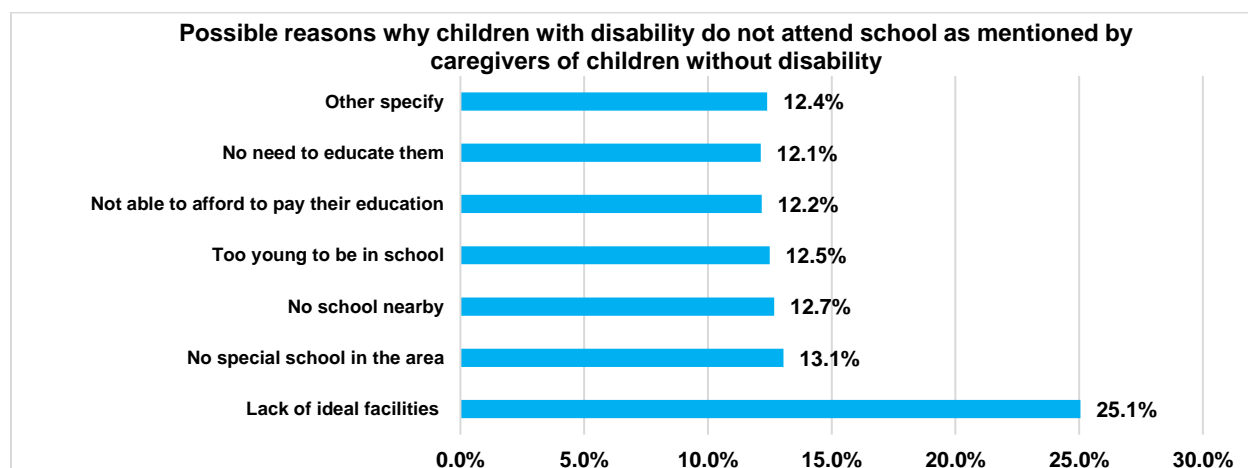
Do you know other children with disability in this area who are NOT attending school?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
No	239	54	37	108	90	58	15	601
	74.7%	91.5%	69.8%	90.8%	66.7%	58.0%	28.3%	71.6%
Yes	81	5	16	11	45	42	38	238
	25.3%	8.5%	30.2%	9.2%	33.3%	42.0%	71.7%	28.4%
<b>Total</b>	<b>320</b>	<b>59</b>	<b>53</b>	<b>119</b>	<b>135</b>	<b>100</b>	<b>53</b>	<b>839</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

Asked why they were not attending school, caregivers gave a variety of reasons including lack of ideal learning facilities (n=165,34.4%), lack of special school in the area (n=134,27.9%), too young to attend school (n=68,14.2%), inability to pay for education (n=44,9.2%), no nearby school (n=39,8.1%), and no need to educate them (n=12, 2.5%). However, a majority (n=601,71.6%) were not aware of any children not attending school.



**Figure 5: Reasons why children with disability are not attending school according to their caregivers**

Caregivers of children without disability were also asked if they were aware of any children with disability who did not attend school, to which a small percentage (n=78,19.1%) answered in the affirmative. The caregivers mentioned varied reasons why these children may not be attending school including lack of ideal learning facilities (n=695,25%), no special school in the area (n=362,13.1%), no nearby school (n=352,12.7%), too young to be in school (n=347, 12.5%), inability to pay for their education (n=338, 12.2%) and caregivers did not see the need to educate them (n=337, 12.1%). A majority (n=330,80.1%) were not aware of any children with disability who were not attending school.



**Figure 6: Reasons why children with disability are not attending school as mentioned by caregivers of children without disability**

On whether all children from the areas of jurisdiction of BOMs were attending school, those in four FGDs noted that schools were generally inaccessible to severely or multiple handicapped children. They further noted that children with disability faced the challenge of limited learning resources that are not disability friendly.

While about two-thirds of caregivers (n=216,70.6%) would be willing to enrol their children in school if a chance was available, a significant one-third (n=90,29.4%) were not willing. Overall, children with disability continued to register low numbers in school as reported by a teacher, *"Getting a child with disabilities in our school is a rare occurrence here in Turkana-west sub-county. For instance, in the school where I teach, a school that is integrated based on our education policy we only have 15 kids with disabilities, and trust me there are more children with disabilities in the area."*

This has resulted in low transition rates across all levels of education in Turkana West Sub-County

#### *Distance to nearest school for children with disability*

On the distance to the nearest school that children with disabilities could access, slightly over half of the caregivers (n=441,51.1%) said that the nearest school was less than half an hour's walk from their homes. Another (n=351,40.7%) said the nearest school was between half an hour to one hour walk from home while a few (n=70, 8.1% said the nearest school was more than an hour's walk from home.

Half an hour to an hour's walk to the nearest school was reported by about half the caregivers in Letea, Nanaam, and Songot wards as seen below. More than an hour's walk was reported by close to a third of caregivers in Kakuma, about 42% of those in Lokichogio.

**Table 4: Distance to the nearest school a child with disability can attend by Ward**

How far is the nearest school children with disability can attend?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
About an hour's walk away	20	1	1	2	2	1	7	34
	6.1%	1.8%	1.8%	1.6%	1.4%	1.0%	13.2%	3.9%
Between 30-45 minutes' walk	71	3	25	36	44	30	18	227
	21.7%	5.0%	43.9%	29.1%	31.4%	29.7%	34.0%	26.3%
Between 45 minutes to 60 minutes' walk	32	0	4	7	12	26	9	90
	9.8%	0.0%	7.0%	5.7%	8.6%	25.7%	17.0%	10.4%
Less than 10 minutes' walk away	15	31	8	2	13	14	1	84
	4.6%	51.7%	14.0%	1.6%	9.3%	13.9%	1.9%	9.7%
Less than 20 minutes' walk away	67	22	5	22	34	8	0	158
	20.5%	36.7%	8.8%	17.7%	24.3%	7.9%	0.0%	18.3%
Less than 30 minutes' walk away	93	0	12	52	32	7	3	199
	28.4%	0.0%	21.1%	41.9%	22.9%	6.9%	5.7%	23.1%
More than an hour's walk away	29	3	2	3	3	15	15	70
	8.9%	5.0%	3.5%	2.4%	2.1%	14.9%	28.3%	8.1%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

Overall, this finding suggests that more than half of children with disabilities in Turkana West Sub-County still had difficulties accessing learning facilities. This was mirrored in findings with caregivers of children without disabilities, more than half of whom (n=243, 59.8%) said that the nearest school that children with disabilities could attend was less than a 30-minute' walk from their village. Another (n=137,33.6%), said that the nearest school for children with disability was between half an hour to an hour walk from the village. A few (n=28, 6.9%) reported the nearest school was more than an hour's walk away.

#### *Nature of school learning environment*

Caregivers of children with disabilities were asked their opinions, based on their observations, on how friendly the learning environment was, in the schools, their children are enrolled in or would enrol in. To this, more than two-thirds (n=599,69.5%), said that the school learning environment was not friendly for children with disability. A few (n=128,14.9%) reported that it was friendly while (n=135,15.7%) did not know. This finding was mirrored across all wards. When asked about the main challenges children with disabilities face accessing education, the caregivers shared a number of them as shown in the table below. Children in FGDs also observed that not all children with disability attend school. They said that those with intellectual difficulties often lose their way to or from school, and take time to understand compared to other children. Those with severe physical disabilities also faced challenges accessing education facilities.

**Table 5: Challenges in accessing education by children with disabilities**

Views by caregivers of children with disability	Frequency	Percent
Long distances to available schools	406	15.2%
The inability of parents to raise the required money	419	15.7%
Lack of special needs teachers in most schools	600	22.5%
Lack of special needs facilities in most schools	545	20.4%
Stigma the children receive in school/community	323	12.1%
Refusal by parents to enroll children in school	147	5.5%
Fear of family stigmatization by the community	171	6.4%
Not of school-going age	28	1.1%
Others specify	32	1.2%

Similar sentiments were echoed by caregivers of children without disabilities, with more than two-thirds (n=271,66.4%) reporting that the school learning environment was not friendly to children with disabilities. A few others (n=49,12%) were of a contrary view while another (n=88,21.6%) did not know. The caregivers shared several challenges, which in their opinion children with disabilities faced while trying to access education. These are shown in the table below.

**Table 6: Challenges in accessing education by children with disabilities**

Views by caregivers of children without disabilities	Frequency	Percent
Long distance to available schools	244	20.8%
Lack of special needs teachers in most schools	289	24.7%
Lack of special needs teaching aids in most schools	265	22.6%
Stigma the children receive in school and community	178	15.2%
Refusal by parents to enrol children in school	88	7.5%
Fear of family stigmatization by the community	90	7.7%
Other specify	17	1.5%

A male participant in an FGD noted the lack of capacity in schools to provide relevant education to children with disability.

*'Children with disability need special care and attention for them to succeed in school and none of our local schools offer such. If the local schools are struggling to teach children without disabilities, how can you expect them to teach children with disability?'*

Most caregivers of children without disabilities (n=355,87.0%) said that the learning facilities for children with disabilities are inadequate. They cited various challenges they would need improved including access roads, accessibility of special schools, availability of relevant learning equipment, few and ill-equipped classrooms, few teachers, availability of funds to support the children's learning, lack or shortage of assistive devices, low community awareness about people with disabilities, proper diet and adequate food challenges and lack of equipment and playgrounds for children with disability.

Furthermore, a majority of caregivers of children without disabilities believed that education institutions were inadequate because government had not established them (n=353,41.5%), no NGO or CBO had established any (n=172,20.2%), it was costly to set up a school for children with disability (n=97,11.4%), there is no need for a school for children with disability (n=68,8%) and that children with disability were not many in the community (n=80,9.4%). Children in FGDs noted that boarding schools would serve them better because they would limit the distance such children would need to travel. They would also do with a varied diet, given that some have

difficulty eating maize and beans. The children also called for the provision of assistive devices for the children as well as special education teachers to help them learn just like other children.



Programme staff issues a child with an assistive device. Photo courtesy of WKP

On whether children with disability are treated the same way as other children in school, children interviewed in all groups responded to the contrary. One child noted,

*'Some children with disability are just in class to pass the time. They take time to understand things and not all teachers have the patience. Teachers therefore concentrate more on the other children'*

Caregivers of children without disabilities believe that children with disabilities who attend school are integrated into general classrooms with other children as mentioned by (n=310,76%). A few others (n=54,13.2%) were of the view that the children attend special classrooms while another (n=44,10.8%) did not know.

When asked if children with disability were likely to succeed in school compared to other children, adult male and female participants in FGDs responded to the contrary. A male participant for example noted that,

*The reason why we are saying children with disability are less likely to perform in school as compared to other children is because of the kind of infrastructure our schools have. I don't know if there is any school in Turkana that is well-equipped for children with disabilities; even the teachers in these schools, are they qualified to teach children with disability?'*

A female participant noted,

*'Parents with children with disabilities take their kids to school purposely because of the feeding program rather than to learn. Most parents believe that when a child has any form of disability, they are unable to comprehend anything thus their sole purpose is for them to be fed.'*

In all FGDs with BOM members, participants were unanimous that children with disability were less likely to succeed in school compared to other children. They noted that this was because of several reasons including negative cultural beliefs about the children, lack of adequate resources to support their education, and generally poor learning infrastructure.

Concerning training of the Board of Management (BOMs) on matters relating to children with disability, findings show that half of the BOM members met in FGDs (4 FGDs) reported that not all BOM members had been trained, compared to three FGDs who mentioned that all BOM members have been trained. When asked what new or additional training would be useful for them, BOM members mentioned training on inclusive education, care for children with disability, and sign language. Key informants further noted the importance of training parents and caregivers on inclusive education given that learning for children takes place even from home.



*Training session for parents and caregivers: Photo courtesy of WKP*

The table below presents a summary of a few key indicators reviewed from the Waldorf Kakuma Project's school baseline assessment report. The data shows that in most wards reasonable number of teachers had been trained in Competency Based Curriculum (CBC) and ECDE. A majority of teachers do not have any training in special needs education. In most wards, the most common form of disability among learners is physical except in Kakuma camp where there are more children with visual challenges. All schools in most wards and a majority in a few wards benefit from the school feeding programme.

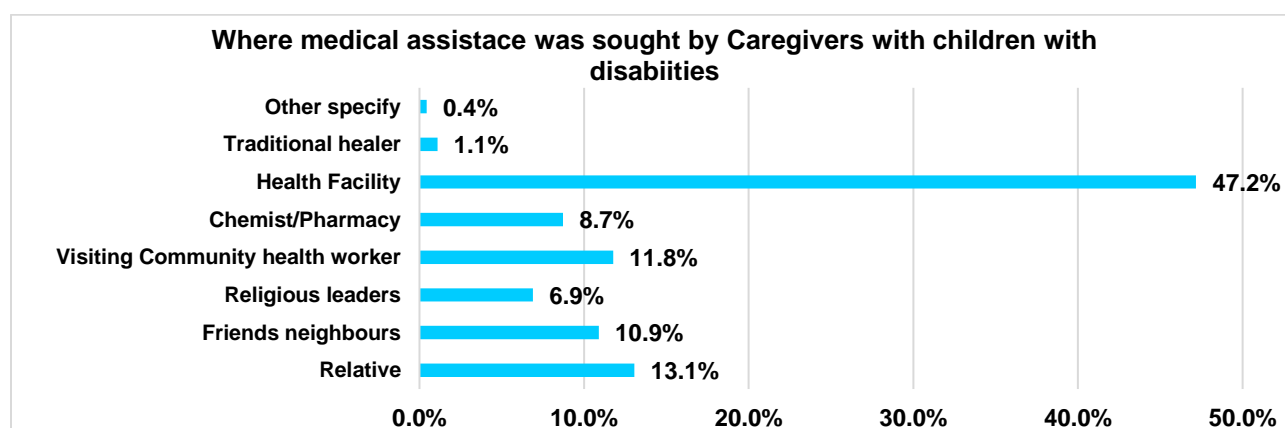
**Table 7: WKP Baseline Assessment: School situation in Turkana West Sub-County**

Area	Total			With disabilities			Trained			Untrained			SNE Trained			CBC trained		
	M	F	T	M	F	T	M	F	T	M	F	T	M	F	T	M	F	T
Kakuma (host)	10	22	32	1	4	5	10	20	30	0	2	2	1	2	3	9	21	30
Lopur	8	4	12	1	0	1	7	4	11	1	0	1	0	0	0	7	3	10
Kalobeyei (host)	12	3	15	2	0	2	12	3	15	0	0	0	0	0	0	12	2	14
Songot	9	5	14	1	0	1	8	5	13	1	0	1	0	0	0	8	4	12
Letea	8	2	10	1	0	1	8	2	10	0	0	0	0	0	0	8	2	10
Lokichoggio	5	9	14	1	1	2	5	9	14	0	0	0	0	0	0	3	7	10
Naanam	8	3	11	0	0	0	8	3	11	0	0	0	0	0	0	6	3	9
Kalobeyei settlement	10	16	26	0	0	0	3	3	6	7	13	20	2	1	3	9	16	25
Kakuma camp	68	45	113	3	2	5	46	22	68	19	26	45	15	7	22	67	41	108
<b>Total</b>	<b>138</b>	<b>109</b>	<b>247</b>	<b>10</b>	<b>7</b>	<b>17</b>	<b>107</b>	<b>71</b>	<b>178</b>	<b>28</b>	<b>41</b>	<b>69</b>	<b>18</b>	<b>10</b>	<b>28</b>	<b>129</b>	<b>99</b>	<b>228</b>

According to the baseline study, there were 247 teachers in 108 ECD centers at the time that the assessment was carried out. Of this number, 138 teachers or 55.9% of the total were male while 109 or 44.1% were female. There are few female teachers in the host schools because educating a girl in the community is not a priority. From the assessment, there were 139 teachers (56.3%) in the 19 Kakuma refugee camp and Kalobeyei settlement ECDE centers. The other 108 teachers (43.7%) were spread across the 89 ECDE centers in the host community. Furthermore, there were 17 (10 male and 7 female) teachers with disabilities across all the centers assessed, which represents 6.9% of the total number of teachers.

### 3.3 Provision of health services for children with disability

The provision and access to health services for children with disability in Turkana West Sub-County was explored. Study findings show that health facilities are gaining prominence as preferred healthcare providers for caregivers of children with disabilities. Health facilities received most mentions (n=650,47.2%), from caregivers as the preferred source of advice the last time their child needed health care. Others mentioned were relatives (n=180,13.1%), visiting community health workers (n=162,11.8%), friends/neighbours (n=150,10.9%) chemists or pharmacy (n=120, 8.7%), religious leaders (n=95,7%) and traditional healer (n=15,1.1%). This is seen in the figure below.



**Figure 7: Where caregivers of children with disability sought medical assistance**

Health facilities received the most mentions in Kalobeyei (93.8%), Kakuma (62.7%), Lopur (58.6%), and Nanaam wards (42.3%), and the least mentions in Letea (14%), Songot (17%), and Lokichogio 32.2% as seen in the table below.

**Table 8: Where caregivers of children with disability seek medical assistance by ward**

From where did you seek advice the last time their CHILD was sick or needed healthcare								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
Relative	49	3	29	7	37	12	43	180
	10.6%	4.7%	25.4%	4.6%	16.7%	7.1%	22.2%	13.1%
Friends neighbours	27	0	37	21	5	29	31	150
	5.8%	0.0%	32.5%	13.8%	2.3%	17.3%	16.0%	10.9%
Religious leaders	24	0	10	11	10	13	27	95
	5.2%	0.0%	8.8%	7.2%	4.5%	7.7%	13.9%	6.9%
Visiting Community health worker	25	1	15	54	13	30	24	162
	5.4%	1.6%	13.2%	35.5%	5.9%	17.9%	12.4%	11.8%
Chemist/Pharmacy	44	0	2	10	27	8	29	120
	9.5%	0.0%	1.8%	6.6%	12.2%	4.8%	15.0%	8.7%
Health Facility	291	60	16	49	130	71	33	650
	62.7%	93.8%	14.0%	32.2%	58.6%	42.3%	17.0%	47.2%
Traditional healer	2	0	5	0	0	1	7	15
	0.4%	0.0%	4.4%	0.0%	0.0%	0.6%	3.6%	1.1%
Other specify	2	0	0	0	0	4	0	6
	0.4%	0.0%	0.0%	0.0%	0.0%	2.4%	0.0%	0.4%
<b>Total</b>	<b>464</b>	<b>64</b>	<b>114</b>	<b>152</b>	<b>222</b>	<b>168</b>	<b>194</b>	<b>1378</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

A similar trend was seen in responses from caregivers of children without disabilities, most of whom mentioned health facilities (301,45.4%), followed by relatives (n=89,13.4%), friends/neighbours (n=80,12.1%), visiting community health workers and chemist/pharmacy (n=63,9.5%) respectively, religious leaders (n=56,8.5%) and traditional healer (n=11,1.7%).

Discussions with community members in FGDs were a sharp contrast to the survey findings. The discussions revealed that traditional medicine was still very common and popular in Turkana West, with many people preferring to seek health care from traditional healers because they were accessible, cheaper, and had the traditional herbs. One FGD participant noted,

*"In our area, we do not visit the hospitals, you can even visit the nearest health facility right now and you will find it empty, this is because most people believe in traditional medicine and that is our culture. Convincing people to go to a hospital is not easy. Now if people generally do not go to a hospital do you think they will take their children?"*

Children in all FGDs reported that children with disabilities were taken to hospitals for treatment. They nevertheless also reported that the children experienced several challenges accessing treatment, including distances covered, affordability, and lack of medicine in the health facilities.

Discussions with government medical officers and other stakeholders indicated that people tend to go to health facilities when their conditions worsen, when children are too young, or when they have easy access to a health facility. They observed that a majority prefer the traditional medicine men because they are easily accessible. They further cautioned that given such situations, children with disabilities may not benefit from modern technology and approaches to address many of their conditions, some of which could be reversible with the correct, early, and effective diagnosis and management.

### 3.3.1 Health providers

The government (national and county) was the most mentioned provider of health services for caregivers and their children. This was mentioned by (n=686,61.8%) of parents and caregivers of children with disability. Another (n=207,18.7%) mentioned NGOs, (n=117,10.5%) mentioned church/religious groups, (n=43,3.9) mentioned international agencies and (n=10,0.9%) mentioned CBOs. These findings were mirrored in those of parents/caregivers of children without disability. About two-thirds of them (n=306,61.8%), mentioned the government (national and county) as the health services provider for their children, (n=109,22%) mentioned NGOs, (n=36,7.3%) mentioned churches/religious groups, (n=13,2.6%) mentioned international agency and another (n=5,1%) mentioned CBOs. This is seen in the figure below. Others mentioned include chemist and `family.

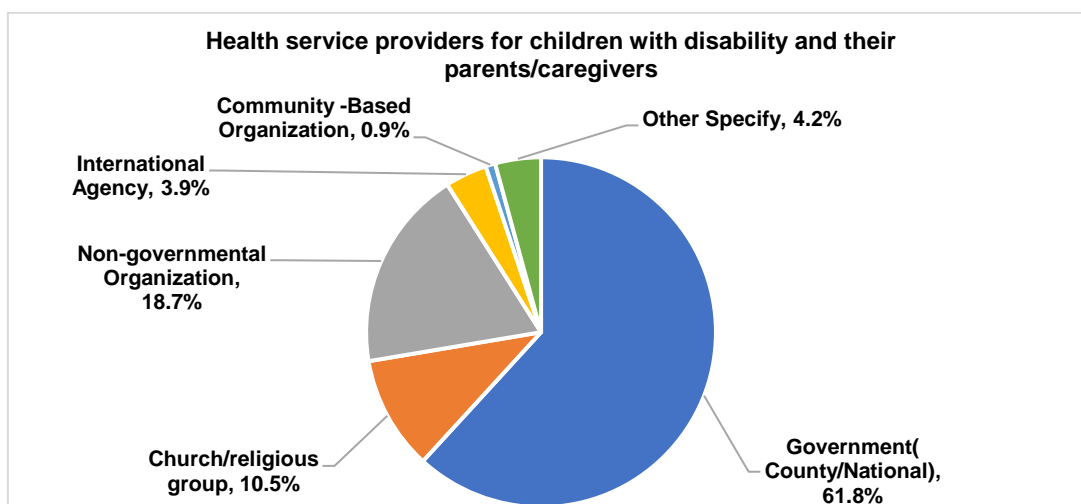


Figure 8: Health service providers in Turkana West Sub-county

### 3.3.2 Physical access to health services

Physical access to health facilities was reported to be in the range of between 20 minutes to an hour's walk for most of the caregivers. Less than half of caregivers of children with disability walked for less than 10-30 minutes to reach the nearest health facility as reported by (n=358,41.5%). Another (n=166,19.3%) walked for between 30 to 45 minutes while (n=135,15.7%) walked for between 45 to 60 minutes. A few caregivers (n=88,10.2%) reported that they walked for about an hour and another (n=115,13.3%) walked for more than an hour as seen in the figure below. More than half the caregivers in Lokichogio (52.4%) said the nearest health facility was more than an hour's walk.

**Table 9: Time to nearest health facility according to caregivers by ward**

How far is the nearest health facility that Your CHILD can attend when unwell?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Popular	Nanaam	Songot	Total
About an hour's walk away	52	2	2	4	5	5	18	88
	15.9%	3.3%	3.5%	3.2%	3.6%	5.0%	34.0%	10.2%
Between 30-45 minutes' walk away.	68	4	12	16	31	23	12	166
	20.8%	6.7%	21.1%	12.9%	22.1%	22.8%	22.6%	19.3%
Between 45 minutes to 60 minutes' walk	46	2	13	6	24	35	9	135
	14.1%	3.3%	22.8%	4.8%	17.1%	34.7%	17.0%	15.7%
Less than 10 minutes' walk away?	11	23	6	1	8	14	0	63
	3.4%	38.3%	10.5%	0.8%	5.7%	13.9%	0.0%	7.3%
Less than 20 minutes' walk away?	68	15	8	7	30	6	2	136
	20.8%	25.0%	14.0%	5.7%	21.4%	5.9%	3.8%	15.8%
Less than 30 minutes' walk away?	74	0	12	25	37	7	4	159
	22.6%	0.0%	21.1%	20.2%	26.4%	6.9%	7.6%	18.5%
More than an hour's walk away	8	14	4	65	5	11	8	115
	2.5%	23.3%	7.0%	52.4%	3.6%	10.9%	15.1%	13.3%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

This trend was mirrored in interviews with caregivers of children without disability as seen below. There were however slightly more caregivers of children without disability who did shorter distances such as less than 10 minutes' walk, and slightly more caregivers of children with disabilities doing more than an hour walk to the nearest health facility. This would suggest that overall, parents/caregivers of children with disability tended to walk longer to the nearest health facility, perhaps in search of a facility that may have some capacity to accommodate their children.

Longer distances were reported by caregivers as a deterrent to seeking appropriate health care. Parents or caregivers may simply not be able to get their children to the health facilities, especially where children are not able to walk and lack supportive devices.

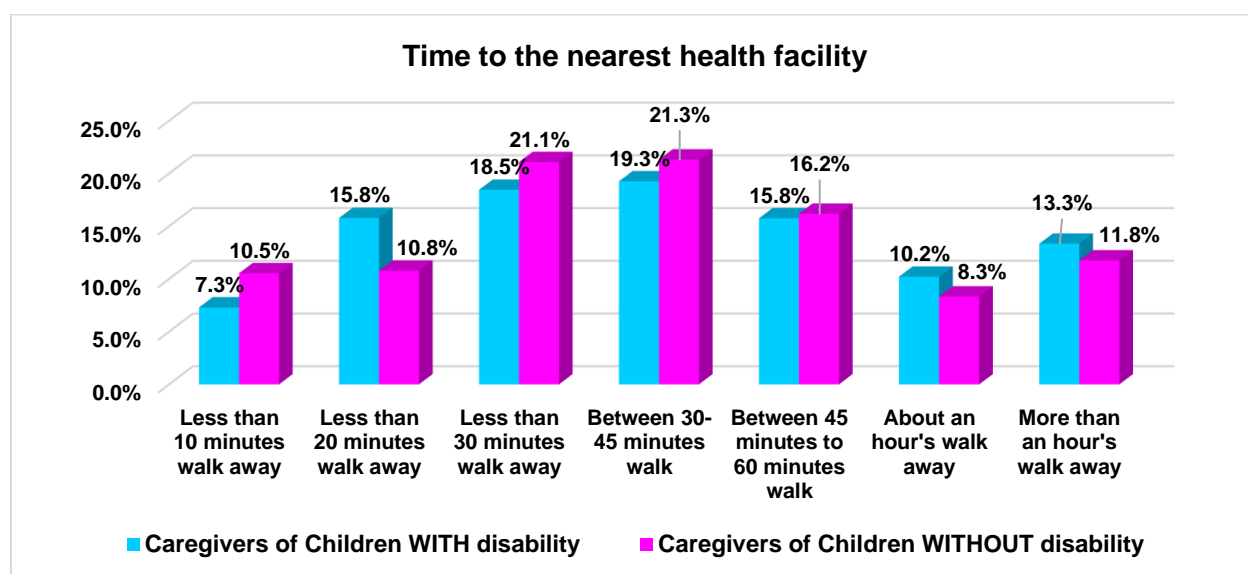


Figure 9: Time taken to the nearest health facility

Similarly given the hot weather and limited and poor road infrastructure, physical movement was noted to be a general challenge in the sub-county. Furthermore, findings on several other parameters besides distance to the health facility show a different story. All caregivers were of the view that most of the requisite services were not available in the accessible health facilities as seen below.

Table 10: Caregivers views of provision of health services for children with disability

Parameter		Caregivers of Children WITH disability		Caregivers of Children WITHOUT disability	
		n	%	n	%
Does the nearest facility provide specialised treatment?	No	741	86.0%	282	69.1%
	Yes	121	14.0%	47	11.5%
	Don't Know			79	19.4%
Does the health facility have qualified personnel?	No	745	86.4%	293	71.8%
	Yes	117	13.6%	42	10.3%
	Don't Know			73	17.9%
Does the health facility have assistive technology or equipment?	No	742	88.4%	310	76%
	Yes	97	11.6%	49	12%
	Don't Know			49	12%
Does the facility have separate clinics for children with special medical attention?	No	795	95%	327	80.2%
	Yes	44	5%	28	6.9%
	Don't Know			53	13%

From the findings, a majority of caregivers reported that the health facilities did not have adequate equipment and personnel to handle the special needs of children with disabilities. Besides the health facility, a majority of caregivers with children with disabilities (n=790,94.2%) reported that they did not have access to assistive technology such as wheelchairs and hearing aids. A few who reported having access (n=49,5.8%) received them either from NGOs, County government, CBOs, or a faith-based organisation.

Caregivers shared several challenges they encounter while accessing health services for their children. Key among the most mentioned includes lack of specialised health services, distance to specialised health services, lack of specialised personnel, adequate equipment, and cost of health services. This is seen below. The findings were mirrored in responses from caregivers of children without disability.

**Table 11: Challenges Caregivers Face Accessing Health Services**

Views by caregivers with	Children WITH disabilities		Children WITHOUT disabilities	
	Frequency	Percent	Frequency	Percent
Specialized health services are not available in this area	580	22.8%	294	24.3%
Specialized health services are too far	532	20.9%	242	20.0%
Health services do not have specialized personnel.	527	20.7%	261	21.6%
Health services do not have adequate equipment	539	21.2%	244	20.2%
Available health services are too costly	301	11.8%	130	10.7%
I am not aware of all the services that my child needs	43	1.7%	20	1.7%
Others specify	22	0.9%	20	1.7%

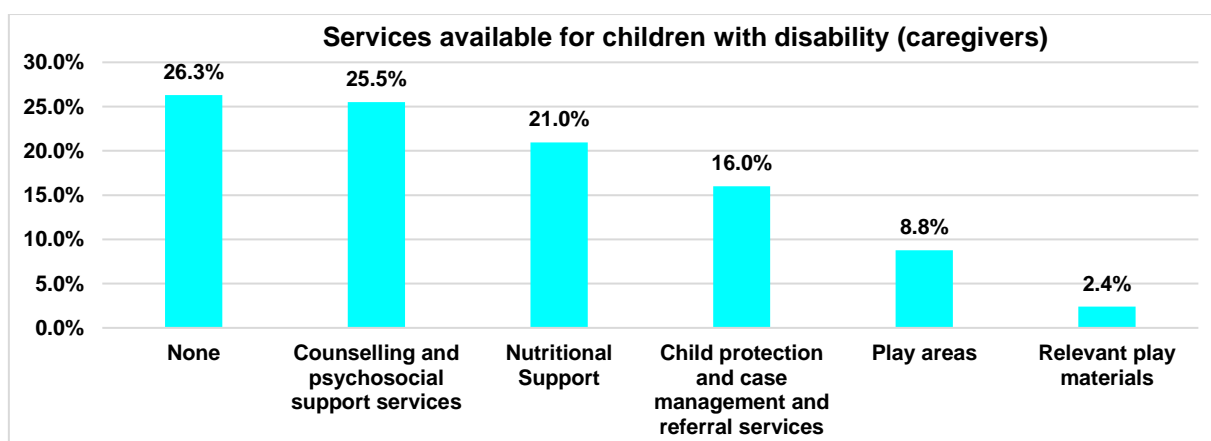
This was also echoed in FGD discussions with adult community members where participants observed that while health facilities exist in the sub-county, distance to the facilities discouraged people from seeking health services. One respondent said;

*"I cannot sit here and lie that we do not have a health facility in our area, we have one, but the problem is the distance to the facility from the village. Now, consider a parent having a child with disability who is unable to walk and has to be carried to a health facility, it becomes almost impossible for them to access the hospitals"*

### 3.4 Collaborative psychosocial and safety support systems for children with disabilities

#### 3.4.1 Available services

The study sought to understand from caregivers of children with disabilities the nature of psychosocial and safety support services available for children and them. Counseling and psychosocial support services were the most mentioned by (n=279,25.5%), followed by nutritional support reported by (n=229,21%). Others mentioned were child protection, case management, referral services, play materials, and play areas as seen below. Slightly over a quarter of caregivers, (n=287,26.3%) said there were no services available in the community.



**Figure 10: Services available to children with disabilities**

These findings were mirrored in interviews with caregivers of children without disabilities. However, a slightly higher proportion of these caregivers (n=178,32.1%) reported that no services were available. Counselling and psychosocial support services were the most mentioned services (n=133,23.9%) followed by nutritional support (n=90,16.2%), child protection, case management, and referral services (n=71,12.8%), play areas (n=29,5.2%) and relevant play materials (n=12,2.2%). Counselling and psychosocial support were the most mentioned services in Letea ward (66.1%) and in Kalobeyei (65.2%).

**Table 12: Services available for caregivers of children with disability by ward**

Type of services are available for caregivers of Children with Disability								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
Nutritional support	36 9.6%	11 12.4%	3 4.8%	42 29.2%	32 16.1%	58 41.7%	11 10.9%	193 17.4%
Counseling and psychosocial support services	122 32.7%	58 65.2%	41 66.1%	8 5.6%	60 30.2%	28 20.1%	24 23.8%	341 30.8%
Government cash-in-kind support programs	27 7.2%	4 4.5%	4 6.5%	4 2.8%	23 11.6%	11 7.9%	20 19.8%	93 8.4%
NGO/non-state cash or in-kind support programs	17 4.6%	7 7.9%	1 1.6%	0 0.0%	4 2.0%	0 0.0%	14 13.9%	43 3.9%
Training programs for caregivers of children living with disability	28 7.5%	7 7.9%	8 12.9%	6 4.2%	42 21.1%	2 1.4%	10 9.9%	103 9.3%
Social support groups	27 7.2%	1 1.1%	0 0.0%	7 4.9%	1 0.5%	0 0.0%	2 2.0%	38 3.4%
Others specify	116 31.1%	1 1.1%	5 8.1%	77 53.5%	37 18.6%	40 28.8%	20 19.8%	296 26.7%
<b>Total</b>	<b>373</b> <b>100.00</b>	<b>89</b> <b>100.00</b>	<b>62</b> <b>100.00</b>	<b>144</b> <b>100.00</b>	<b>199</b> <b>100.00</b>	<b>139</b> <b>100.00</b>	<b>101</b> <b>100.00</b>	<b>1107</b> <b>100.00</b>

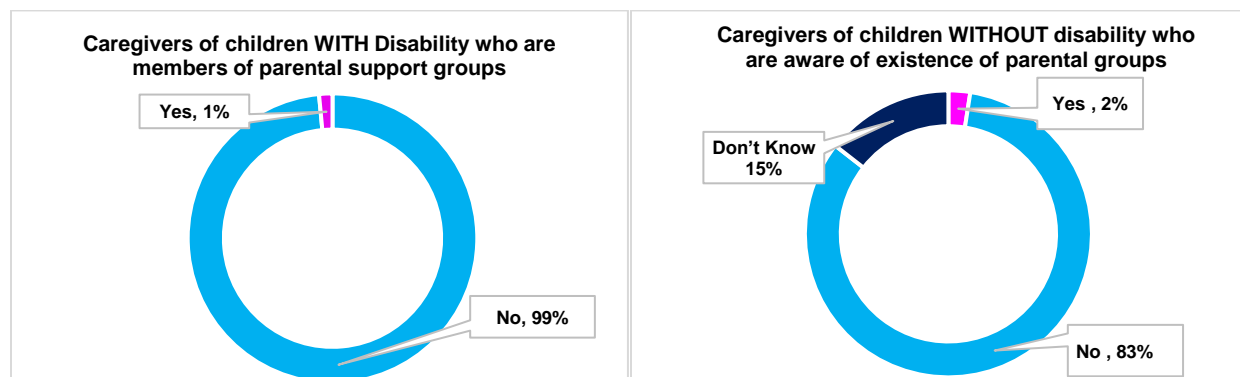
Services available to caregivers were also sought. About a third (n=341,30.8%) of caregivers of children with disabilities mentioned counselling and psychosocial support. Another (n=193,17.4%) reported nutritional support, (n=103,9.3%) mentioned training programs for caregivers, (n=93,8.4%) mentioned government cash in kind support programs, (n=43,3.9%) mentioned NGO/non-state-cash or in-kind support, and (n=38,3.4%) mentioned social support groups. Close to a third of caregivers (n=296,26.7%) said that there were no services available. Similarities were noted in interviews with caregivers of children without disabilities, who mostly mentioned counselling and psychosocial support services, (n=137,24.7%), followed by nutritional support (n=65,11.7%), government cash-in-kind support programmes (n=52,9.4%), training programmes for caregivers (n=45,8.1%), social support programmes (n=10,1.8%) and another (n=36,6.5%) did not know of any.

This finding indicates that social support groups were not a common occurrence among parents/caregivers of children with disability nor were they known to other caregivers. This mirrors the finding below on membership to social support groups.

### 3.4.2 Membership in parental support groups

Parents and caregivers have no forums for mutual emotional, practical, and informational support. Almost all caregivers of children with disabilities (n=826,98.5%) were not members of a parental

support group. However, (n=13,1.5%) were members of social support groups. A few of these groups were mentioned. They include *Atonyoutu Disabled Group*, *Kiwanja Ndege Disabled Group*, *Lokudule Disability Group*, *Lomidat Disability Group*, *Turkana West Disabled Group*, and *Ngikangwalak Self Help Group*. Similarly, most caregivers of children without disabilities (n=339,83.1%) were not aware of any parental support groups for parents or caregivers of children with disabilities in their areas. This is seen in the figure below.



**Figure 11: Caregivers in support groups and caregivers aware of the existence of support groups**

Discussions with key informants echoed the importance of social support for parents/caregivers. They observed that in situations where caregivers lack adequate and affordable health, education, and rehabilitation services for their children, then social support groups help caregivers share experiences and ideas. They were also noted to be forums where caregivers offer each other comfort, understanding, and consolation whenever they face stigma, discrimination, and isolation from their families, communities, and society due to negative attitudes and beliefs about disability. They also offer a forum for caregivers to talk and release their stress, fatigue, and depression due to the physical and emotional demands and challenges of caregiving. A key informant noted,

*“Such social groups can provide a safe and supportive space for parents and caregivers to share their feelings, experiences, and challenges, and to receive empathy, encouragement, and advice from others who understand their situation. The context in Turkana is challenging, but mutual support groups should be supported and encouraged”.*

Another key informant argued that,

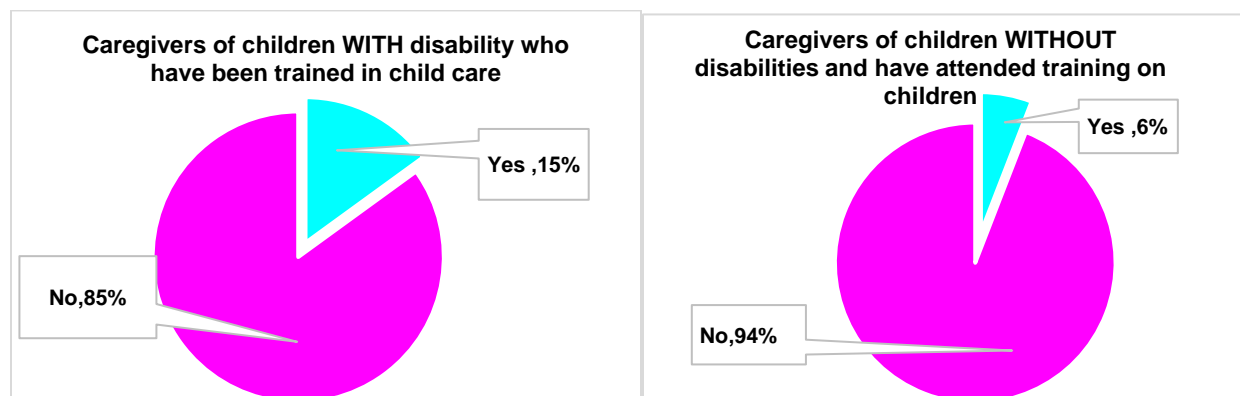
*“Support groups for caregivers can be very good forums where parents and caregivers can be empowered to advocate for their rights and needs and to champion for provision of resources and services for themselves and their children”.*

Parents and caregivers in FGDs further noted that such social groups would be the most practical forums where they can be trained and supported to improve their knowledge and skills, on disability, health, education, and caregiving.

#### *Training in the care of children with disabilities*

Findings show that a majority of caregivers with children with disabilities (n=710,84.6%) had not benefitted from training in caring for their child. The (n=129,15.4%) who had attended some training reported to have been trained by an NGO, an international organization, or the county government. It is further noted that almost all caregivers of children without disability had not attended any training about children with disability, as reported by (n=384,94.1%). This is seen below.

Organizations mentioned to have provided the training appear to cut across caregivers of children with and without disability. They include Humanity and Inclusion, Child Fund, County government, Danish Refugee Council, Waldorf Kakuma Project, Handicap International, Jesuit Refugee Services, Lutheran World Federation, Kenya Red Cross Society, UNICEF, Windle Trust International, World Vision, Catholic Diocese, UNHCR, Save the Children and USAID-Nawiri Programme.



**Figure 12: Caregivers who have been trained in child care**

Lack of community knowledge and understanding of children with disability was noted to have serious consequences on the children with disability and their families. Interviews with key informants, for example, noted that children with disability may fail to enrol in school because of stigma, discrimination, bullying, and lack of financial support, facilities, materials, and trained staff. They further noted that children and their families often face social exclusion and isolation, due to the negative attitudes and beliefs about disability that unsensitized family members, communities, and society hold towards disability, due to a lack of awareness and advocacy on disability rights and issues. As such children of parents with disability often withdraw and hide their children from the community, which further stigmatizes and traumatises the children.

### 3.4.3 Availability of play materials

More than half of the caregivers of children with disability (n=508,58.9%) reported that their children had play materials at their homes, while a significant (n=354,41.1%) said their children did not have any play materials. This finding was mirrored by findings from caregivers of children without disabilities, half of whom (n=205,50.3%) reported seeing children with disability playing with materials in their community. The other half (n=203,49.8%) had not seen children with disability play with materials. Furthermore, slightly more than half (n=221,54.2%) of caregivers of children without disabilities had seen children with disabilities play with other children in the community, while (n=187,45.8%) had not seen these children play with others. This finding suggests that about half of children with disabilities were actively involved in play, while close to half were not.

Discussions with children reported that children with disability are normally involved in song and storytelling, and to an extent physical games such as football for children with mild disability. In most cases, however, children with disability are often excluded from most games that children play. One child noted.

*'I have a physical disability whereby one of my legs has a problem and I cannot run. As compared to the other children, I am often excluded from certain games due to my disability...'*



Children engaging in play: Photo Courtesy WKP

Experts emphasize the importance of play for children with disabilities. They observe that play can help them develop and improve various skills and abilities, such as social-emotional, communication, and physical skills. It can also help children with disabilities have fun and feel included, supported, and cared for by others. Play can also reduce stress, anxiety, and depression, and enhance creativity, curiosity, and problem-solving abilities while fostering inclusion and participation of children with disabilities in their communities, and promoting positive values and attitudes, about disability<sup>57</sup>.

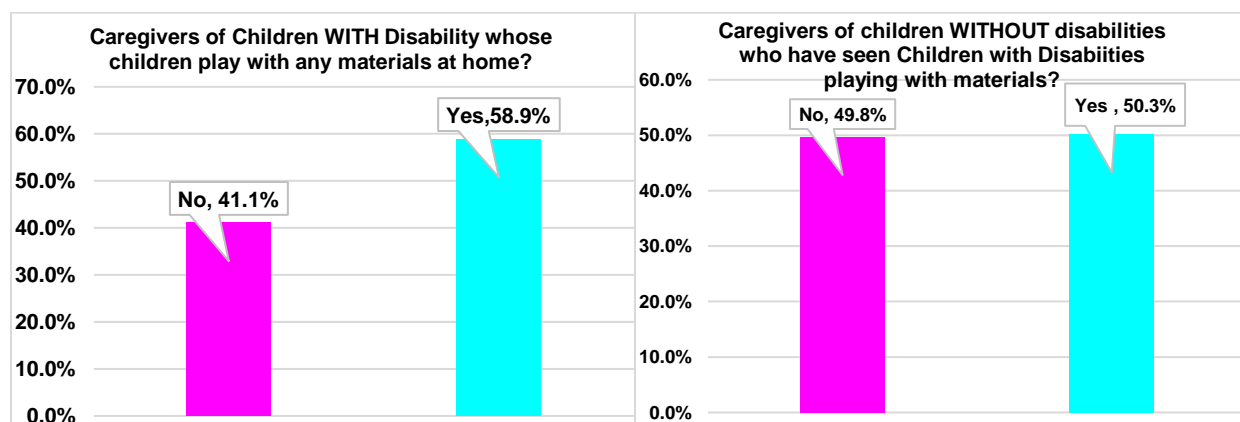


Figure 13: Caregivers of children with disability who report that their child has play materials and those who see children with disability play with materials

Discussions with key informants indicated that lack of play for children with disability can have negative consequences for their development, well-being, and inclusion. They might for example have fewer opportunities to learn and practice social-emotional, physical, and communication

<sup>57</sup> <https://www.ttac.edu.edu/Articles/play.html>

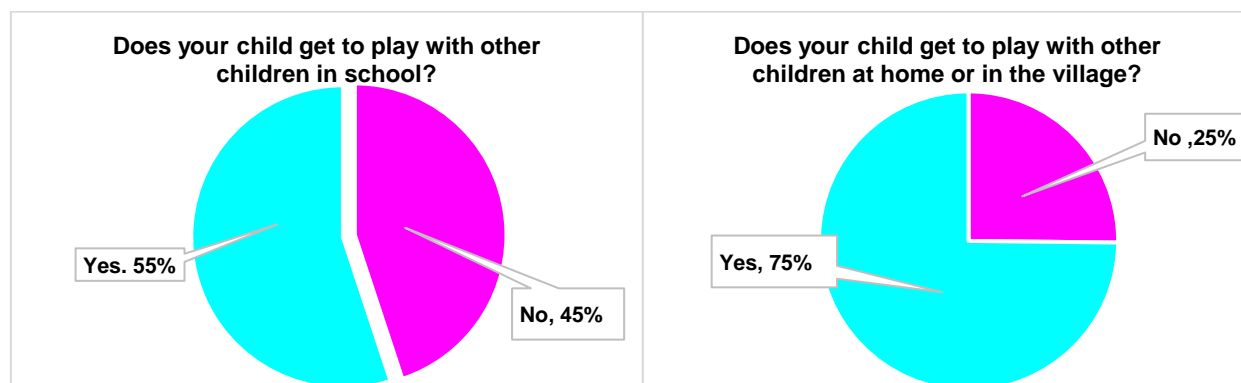
skills essential for their growth. Lack of play could also lead to reduced self-esteem, confidence, and happiness, and higher levels of stress, anxiety, and depression, in addition to limited exposure to diverse and stimulating environments, experiences, and activities that can enhance their creativity, curiosity, and problem-solving abilities<sup>58</sup>. A key informant noted that,

*“...when a child with disability does not play with others, it denies them a chance to establish meaningful and supportive relationships with friends, family members, and other adults. They therefore do not feel as if they belong or are accepted in their communities”*

Providing children with disabilities with play materials that are practical and adaptable to their context, teaching them how to play, and ensuring that they have a safe and supportive play environment is essential in promoting play by all or most children with disability in Turkana West Sub County.

Several materials that children with disabilities play with were mentioned by their parents/caregivers. They include random items picked from the ground (n=319,33.9%), toys made or found by the children (n=245,26%), toys made by an adult at home or within the community (n=161,17.1%), toys from a market or shop (n=114,12.1%), and things that make or play music (n=74,7.9%). The trend in the responses was noted among caregivers of children without disability, in addition to toys provided by an NGO/CBO. The finding shows that more than a third of caregivers report that children played with random items they picked from the ground.

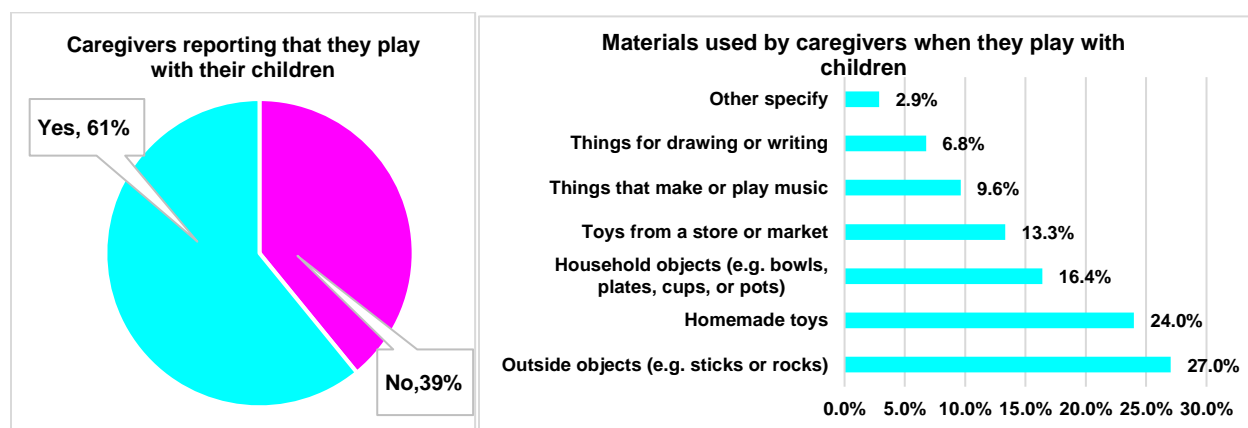
More than half of caregivers of children with disabilities (n=496,57.5%) reported that their children did not play with any materials in school. However, more than half (n=476,55.2%) reported that their children got to play with other children in school, compared to (n=386,44.8%) who did not. Another (n=645,74.8%) said that their children played with others at home or in the village and (n=217,25.2%) did not. This suggests that comparatively, more children got to play with others at home or in the villages compared to schools. This could imply that children with disabilities might be enjoying a safer play environment at home and in the villages compared to schools. This finding is seen in the figure below.



**Figure 14: Caregivers whose children get to play in school and at home**

Furthermore, about two-thirds of caregivers of children with disabilities (n=525,60.9%), reported that they play with their children, but a significant (n=337,39.1%) do not. About a quarter of the caregivers (n=292,27%) said that they use objects they collected outside to play, such as rocks and sticks. Another (n=259,24%) used homemade toys while (n=177,16.4%) used household objects (e.g. bowls, plates, cups, or pots). This is seen below.

<sup>58</sup> [https://www.brighthubeducation.com/special-ed-inclusion-strategies/129109-how-disabilities-affect-the-development-of-play-skills-in-young-children/#google\\_vignette](https://www.brighthubeducation.com/special-ed-inclusion-strategies/129109-how-disabilities-affect-the-development-of-play-skills-in-young-children/#google_vignette)



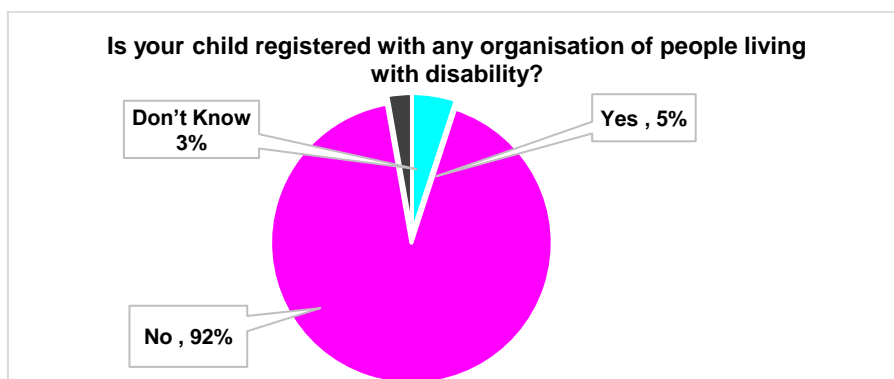
**Figure 15: Caregivers who play with their children and the materials they use to play**

Findings further show that more than three-quarters of caregivers of children without disabilities (n=324,79.4%) had not had a chance to play with children with disabilities in their homes or around the villages.

### 3.5 Registration of children and community support systems

Registration with an organization of people with disabilities such as the National Council of People with Disability (NCPWD)<sup>59</sup> is essential. It provides the opportunity for children with disabilities and their caregivers to benefit from different support services provided by and through the Council. NCPWD promotes and protects equalization of opportunities and realization of human rights for PWDs to live decent livelihoods.

Study findings show a majority of caregivers saying that their children were not registered with any organization for people with disabilities as reported by (n=794,92.1%). Another (n=25,2.9%) did not know if their children were registered. Of the 43 caregivers who reported that their children were registered, 35 were registered with the NCPWD.



**Figure 16: Registration with an organization of people with disability**

This suggests that children with disabilities were not effectively benefiting from essential services provided by these organizations. The inaccessibility of the NCPWD was partly to blame for the low level of registration, given that there was only one office in the entire county, located in Lodwar. A majority of those whose children were registered had to travel to Lodwar or they benefited from an outreach registration event. Besides registration, caregivers were not aware of other benefits of registration neither could most identify services they received following the registration. Some of

<sup>59</sup> <https://ncpwd.go.ke/about-us/>

the services mentioned by only a few caregivers (less than 10%) include assistive devices (n=5,8.2%), education assistance, and cash transfer (n=6,9.8%) respectively, and economic empowerment of caregiver and legal advisory services (n=5, 8.2%) respectively. The registered caregivers rate the usefulness of the registration with NCPWD as somewhat useful (n=21,48.8%), very useful (n=12,27.9%), and not useful at all (n=10,23.3%).

Findings from the FGDs further show that caregivers were more aware of organizations that support households with children with disabilities as opposed to the government agency mandated to register them. In one of the discussions, participants mentioned FINN Church Aid, HI, and Waldorf Kakuma Project, as some of the organizations that supported them. They, for example, noted that the assistance they received from these organizations motivated them to take their children with disabilities to school. One respondent said;

*"Sometimes having a child with a disability is like a blessing because those people are eligible to different kinds of support, you might find a parent with a child with disabilities pocketing like ten thousand shillings in a month plus other benefits like food and clothing"*

### 3.6 Knowledge attitudes and perceptions on disability and children with disability

This section analyses the knowledge attitudes and practices towards disability held by the community. These form the basis upon which children with disability are treated and protected.

#### 3.6.1 Knowledge of and attitudes towards types of disability

All caregivers were asked about the types of disabilities that they were aware of. Findings show minimal differences in awareness between caregivers of children with disabilities and those without as seen below. Notably, just slightly over a third (n=162,39.7%) of caregivers of children without disabilities reported that they were aware of a child, in the area they lived in, who had a disability. A majority (n=246,60.3%) were not aware. On the other hand, (n=355,40.8%) of caregivers with children with disabilities were aware of another child in the community with a disability other than their own. More than half (n=516,59.2%) were not aware of any other child with a disability. This suggests limited interactions even between caregivers of children with disability.

**Table 13: Types of disabilities caregivers were aware of**

Types of Disability	Caregivers of Children WITH Disability	Caregivers of children WITHOUT Disability
Hearing impairment	21.6%	19.8%
Visual impairment	20.4%	19.9%
Physical impairment	18.4%	18.6%
Speech impairment	17.5%	17.3%
Intellectual disability	9.9%	9.1%
Chronic Illness	7.5%	8.8%
Epileptic	3.2%	4.1%
Albinism	1.4%	2.1%
Other specify	0.2%	0.4%

Hearing, visual, physical, and speech impairments were the most commonly mentioned types of disability by caregivers with children with disabilities and those without. Findings from the children's FGDs show most children mentioning physical disability and hearing difficulties as the forms of disability they were aware of and the most common in their respective areas. Others mentioned were sight difficulties, speech impairment, and epilepsy. Sight difficulties were mentioned in all FGDs with male and female community members. Others mentioned by male and female community members were physical, mental, hearing difficulties and epilepsy.

As noted in the table below, a quarter of caregivers with children with disability believed that disability was caused by God's plan. However, none of the caregivers of children without disability held a similar view. According to the children interviewed, disability was caused by accidents, natural occurrences from birth, witchcraft, God's will, and curses.

Male community members in FGDs noted that physical disability is a common occurrence across most households. One male community member observed that;

*'In Turkana County, there is a higher number of physical disability than any other form of disability. In almost every family you will find there is a person who has a disability on either their hand or legs and most of them are a result of untreated incidences or neglect from caregivers...'*

Similar sentiments were echoed by female community members. A respondent for example observed that,

*'In this area, physical disability is more common because children do not receive the polio vaccine because they are in pastoral communities where we keep moving from one area to another and sometimes, we end up camping in areas without health facilities'.*

FGDs with BOMs also mentioned physical, mental, sight, and hearing difficulties as the most common forms of disability in the areas they came from. Physical disability and hearing difficulties were the most common forms of disability in schools according to BOMs interviewed. One BOM representative observed that;

*'The most common form of disability in most schools is physical. This is because most schools have no facilities and skills to teach children with other forms of disability. Although we enrol them in school, they are not as many as they do not benefit much from what is taught'*

**Table 14: Causes of disability**

	Caregivers of Children WITH Disability	Caregivers of children WITHOUT Disability
God's will/plan	25.7%	0.0%
Illness or disease	21.0%	25.7%
Accidents	14.8%	22.3%
Family curse	9.3%	11.8%
Witchcraft	6.9%	9.3%
Congenital or birth problems	5.3%	5.3%
Inheritance	4.9%	8.0%
Bad family planning methods	4.9%	6.6%
Ignorance by caregivers	3.9%	4.2%
Wrong treatment	3.7%	6.6%
Other Specify	0.2%	0.2%

Adults in FGDs also mentioned other causes of disability including curses, witchcraft, effects of war, genes, lack of proper and effective services, home deliveries, diseases, lack of vaccinations, failure to attend antenatal clinics, animal and insect bites such as snakes and spiders, and complications during pregnancy and birth. BOM representatives indicated that disease and lack of vaccination which leads to conditions such as polio are among the most common causes of disability. Other causes mentioned by the BOM representatives were the effects of war, accidents, witchcraft, genes, natural occurrences. and botched medical procedures.

Furthermore, the knowledge and attitude of caregivers were further assessed using true, false, and don't know types of questions. The findings show minimal variations between caregivers with children with disabilities and those without.

**Table 15: Caregivers knowledge of and attitude towards children with disability**

	Caregivers of Children WITH Disability			Caregivers of children WITHOUT Disability		
	True	False	Don't know	True	False	Don't know
A disability is always visible physical impairment	45.5%	52.7%	1.8%	52.2%	44.9%	2.9%
Children with disabilities are more likely to be molested and bullied than their peers without disabilities	43.3%	54.0%	2.7%	42.7%	52.2%	5.2%
Children with disabilities are always born like that	24.9%	72.6%	2.5%	36.8%	59.6%	3.7%
Assistive devices cannot help children with disabilities to participate more fully in everyday activities	14.3%	82.1%	3.6%	14.0%	82.4%	3.7%
Children with disabilities are less likely to succeed in school than other children without disabilities	15.3%	81.5%	3.2%	14.5%	81.4%	4.2%
Children with disabilities should be treated differently from other children	26.5%	71.5%	2.0%	34.6%	65.4%	0.0%
Children with disabilities have the same potential as other children	68.1%	29.5%	2.4%	77.2%	22.8%	0.0%
Disability is contagious	0.4%	93.5%	6.1%	2.7%	97.3%	0.0%
People with disabilities are beggars	16.0%	79.1%	4.9%	17.9%	82.1%	0.0%
Children with disability are a burden to the family and society	39.3%	58.7%	2.0%	44.4%	55.6%	0.0%
The larger community in this area fully understands issues about children with disabilities	24.8%	62.5%	12.7%	26.0%	74.0%	0.0%
Disability arises from the mother's gene and not the father's gene	4.4%	85.9%	9.7%	5.0%	95.0%	0.0%
Some parents hide their children with disabilities for fear of being shamed by the community	41.0%	54.6%	4.4%	49.5%	50.5%	0.0%
Parents' or caregivers' failures/negligence lead to having disability	12.4%	83.4%	4.2%	23.0%	77.0%	0.0%
Children with disability cannot engage in community and social activities	13.1%	82.5%	4.4%	17.2%	82.8%	0.0%
Children with disabilities cannot attend ordinary schools	13.7%	83.9%	2.4%	14.0%	86.0%	0.0%
Including children with disabilities in regular classroom settings is a good idea	54.8%	40.4%	4.8%	60.5%	30.5%	0.0%
Children with disabilities do not have the same rights as other children	14.8%	81.4%	3.8%	15.4%	84.6%	0.0%
Children with disabilities should be separated from other children without disabilities	15.4%	81.5%	3.1%	15.7%	84.3%	0.0%
I have fully accepted <Name> as he/she is, and I will fully support them to succeed just like other children	75.2%	23.4%	1.4%			
<Name> fully participates in extracurricular activities in school	39.3%	51.4%	9.3%			
We prevent <Name> from engaging in many games with other children because it is unsafe for him/her	31.3%	64.4%	4.3%			
I am fully involved and aware of <Name's> health/nutrition plan	59.9%	33.6%	6.5%			
<Name> has an education plan	50.6%	39.2%	10.2%			
I am aware and fully involved in <Name's> education plan	53.5%	38.4%	8.1%			
I normally teach other children without disability in this family and the community about disability awareness and inclusion	41.7%	52.7%	5.6%			

### 3.6.2 Practices towards Children with disability

Children in FGDs opined that how children are treated depends on the nature of their disability. Often, they observed, children with severe disability are often treated differently from those with mild disability. Findings from adult FGDs show a consensus that children with disability were more likely to be molested and bullied or taken advantage of compared to children without disability. A female participant noted that,

*'Children with disability are unable to stand up for themselves and hence more likely to be molested. There was a child with hearing difficulties who was unable to express herself and had not been taken to school. They did not understand sign language nor did their caregivers. The girl was sexually abused and ended up getting pregnant at the age of 14 years...'*

When asked if children with disability are treated the same as other children without disability in the community, male participants in FGDs had varied views. Participants in 3 FGDs said that children were not treated equally, while those in 4 FGDs said that it depends on the situation while participants in one FGD said that children are treated equally. A respondent for example noted,

*'Children WITH disability are not treated as other children for example they are not allowed to play with other children. Either their parents prevent them from playing with the other children, their disability does not allow them, or the parents of the other kids stop their children from playing with children with disability.'*

Another male FGD participant further observed that,

*"A child with a disability is seen as a burden as they are unable to do much for themselves so they depend on others in the simplest of tasks. Therefore, they are more likely to be harassed by their peers due to their inability. For example, while growing up my brother had hearing difficulties, he was left out in most activities that children did, and mostly harassed by peers since he did not fit into most of the activities"*

Another male participant in an FGD shared that,

*'I stammer and I never fitted in as a child as most of my peers isolated me because I could not be able to express myself like they did. As a child, it is torturous to be isolated by your peers, as you have no one else to easily and freely interact with'.*

The study further explored practices towards children with disability. Findings from caregivers suggest a general lack of inclusion. A female participant in an FGD noted that,

*'I have a child who is physically disabled and due to his disability, he is unable to play with other children. Whenever he tries to play with them, he is usually not included in the games and sometimes children call him names that relate to his disability'*

In yet another FGD session, adult community members noted that some parents molest and bully their children. One parent noted that,

*'I have been a witness to instances where parents molest their children. In one case, a parent was hiding their disabled child, they kept her inside the house all day and would only be allowed in in the evening when it was dark. Unfortunately, the child succumbed to various complications and died'.*

All BOM representatives were in consensus that children with disability were more likely to be molested and bullied compared to children without disability. They noted that this was because many cannot defend or speak out for themselves, making them an easy target. Similarly more than half of all caregivers were of the view that children with disability are not treated in the same way as those without, that there are no play areas conducive for children with disability, and that they are not included in community events and activities. This is seen below.

**Table 16: Community practices towards children with disability**

	Caregivers of Children WITH Disability		Caregivers of children WITHOUT Disability	
	Yes	No	Yes	No
Do you believe that children with disabilities in this community are treated in the same way as children without disabilities	41.1%	58.9%	39.7%	60.3%
Are there play areas that are conducive for children with disabilities in the community?	25.6%	74.4%	17.9%	82.1%
Are children with disabilities included in community events and activities	42.7%	57.3%	40.2%	59.8%
Are there employment opportunities for adults with disabilities in this community	26.6%	73.4%	23.0%	77.0%
Do you allow your child to freely play with other children in the community	66.5%	33.5%		
Do you allow you're your child to attend school	68.9%	31.1%		
Do parents and caregivers of children with disabilities in this community allow their children to play with others in the community			59.3%	40.7%
Are there schools or learning facilities for children with disabilities in this area?			19.6%	80.4%
Do parents and caregivers of children with disabilities in this community allow them to go to school?			65.2%	34.8%

Discussions in FGDs and analysis of the study findings show that community attitudes and practices towards children and people with disability were anything but positive. This was exacerbated by the retrogressive cultural beliefs and practices. In FGDs with both male and female community members, participants openly associated disability with curses and witchcraft. One respondent said;

*"In our culture, we do not believe that a person is born disabled but rather the actions of their parents are what makes them disabled, for instance, if one of the parents practices witch-craft then they will most probably give birth to a disabled child."*

Additionally, respondents associated disability with bad omens and curses, with most holding the belief that bearing a child with disabilities will result in the loss of livestock as well as getting livestock that are disabled. Therefore, women who gave birth to children with disability were in some areas considered outcasts and were neglected by their male partners. One FGD participant said;

*"My sister has two children who are disabled and she was kicked out by her husband and labelled a bad omen. She had to relocate from the village to Lodwar as she was not accepted at home, and this is so sad for her yet I cannot help her."*

Notably, caregivers are scolded and stigmatised by community members for bearing a child with a disability. As a result, key informants reported that some caregivers opt to hide their children or throw them away in the bushes.

Key informants echoed the need for community education and enhanced communication for social and behavioural change which involves using different media and messages to raise awareness, educate, and persuade the community about the rights, needs, and abilities of children with disability, and to challenge the stigma, discrimination, and stereotypes that they face. Key informants and participants in FGDs gave an example of a local leader and a few other people who had progressed in their careers despite that they had a disability. They called for the engagement of people with disability to showcase and celebrate the achievements and contributions of people with disability, especially children and youth, and provide them with

opportunities and platforms to share their stories, experiences, and perspectives with the community, and to inspire and motivate others.

### 3.6.3 Rights of children with disability

Caregivers were further asked their views on the **rights of children with disability**. A few caregivers of children with disability (n=43,1.1%) and (n=17,1%) of children without disability said that these children have no rights. Several other rights were mentioned by caregivers as shown below.

**Table 17: Rights of children with disability**

What do you think are the rights of children with disability?	Caregivers WITH Children with Disability		Caregivers of children WITHOUT Disability	
	Freq	Percent	Freq	Percent
Children with disability have no rights	43	1.1%	17	1.0%
Right to be treated equally and not to be discriminated against based on their disability	594	15.7%	263	15.7%
Right to express their views and have those views taken into account in all matters that affect them	529	13.9%	230	13.7%
Right to quality education that is inclusive of their disability and allows them to reach their full potential	583	15.4%	259	15.4%
Right to access health care services and rehabilitation services that meet their specific needs	530	14.0%	254	15.1%
Right to be involved in decisions that affect them	376	9.9%	161	9.6%
Right to receive the necessary support to enable them to live with dignity and independence	388	10.3%	176	10.5%
Right to be protected from abuse neglect and exploitation	338	8.9%	149	8.9%
Right to participate in community activities including cultural and recreational activities	294	7.8%	117	6.9%
Other specify	1	0.5%	1	0.1%
Don't know	105	2.8%	53	3.2%

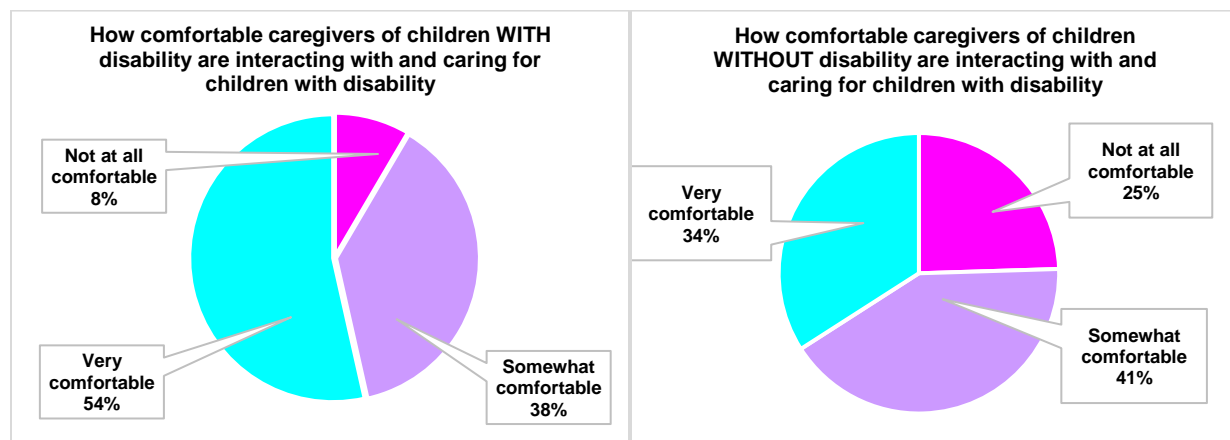
Findings on the rights of children with disability were mirrored across all caregivers suggesting no major variations in knowledge across the caregivers. Similarly, male and female adults participating in FGDs mentioned other rights of children with disability including, the right to eat, the right to get medical attention, the right to inclusion, the right to be loved, the right to equal treatment, the right to good health and right to life. BOM representatives also mentioned the same rights, with the right to eat and the right to education receiving mentions in all the seven FGDs.



Children engaging in an activity: Photo Courtesy of WKP

### 3.6.4 Comfort and Knowledge of caring children with disability

More than half of caregivers of children with disability (n=449,53.5%) are very comfortable caring for children with disability. Another (n=319,38.0%) are somewhat comfortable and a few (n=71,8.5%) are not at all comfortable. On the contrary just above a third of caregivers of children WITHOUT disability (n=139,34.1%) are very comfortable, less than half (n=169,41.4%) are somewhat comfortable and about a quarter (n=100,24.5%) are not at all comfortable. This is seen in the figure below



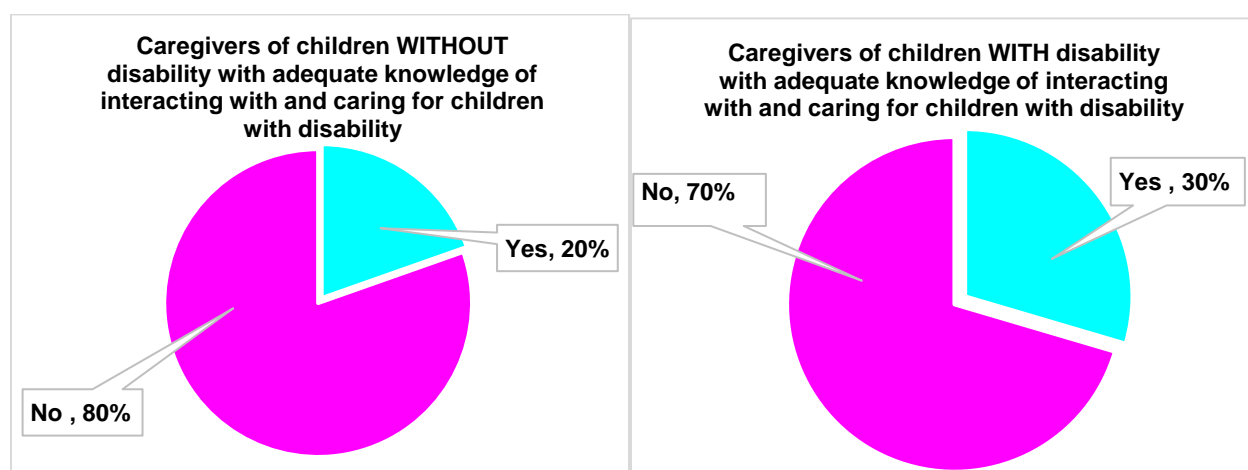
**Figure 17: Level of comfort of caregivers interacting with and caring for children with disability.**

Across wards, all children in Letea and almost three-quarters of caregivers in Kakuma, Lokichogio, Lopur, and Nanaam believed that they did not have adequate knowledge of how to care for children with disability. It was only in Kalobeyei where a majority (n=89.8%) and Songot (n=49.1%) of caregivers reported that they had adequate knowledge of how to care for children with disability. Limited knowledge comprises the quality of care that children with disability receive.

**Table 18: Caregivers with adequate knowledge to care for children with disability by ward**

Do you believe you have adequate knowledge of how to care for children with disability?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
No	231	6	53	88	99	87	27	591
	72.2%	10.2%	100.0%	74.0%	73.3%	87.0%	50.9%	70.4%
Yes	89	53	0	31	36	13	26	248
	27.8%	89.8%	0.0%	26.1%	26.7%	13.0%	49.1%	29.6%
<b>Total</b>	<b>320</b>	<b>59</b>	<b>53</b>	<b>119</b>	<b>135</b>	<b>100</b>	<b>53</b>	<b>839</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

Caregivers of children without disability were asked if they had adequate knowledge to enable them to interact with and care for children with disability. It was concerning that a majority (n=328,80.4%) did not have adequate knowledge and only a minority (n=80,19.6%) said that they knew. The same was mirrored in findings from caregivers of children with disability, more than two-thirds (n=591,70.4%) did not have adequate knowledge of how to care for their children. Just about a third (n=248,29.6%) said that they had adequate knowledge.



**Figure 18: Caregivers with adequate knowledge of how to interact and care for children with disability**

When those with knowledge were asked what their most important source of knowledge on issues related to children with disability was, a third (n=25,31.3%) said radio, (n=13,16.3%) said community health/social workers, and (n=10,12.5%) said other community members and religious leaders respectively. Other sources mentioned were teachers, friends, community meetings, family, posters, newspapers, and other printed materials. Caregivers of children WITH disability said that their most important source of knowledge and information on issues related to disability was radio mentioned by (n=291,34.7%), community health/social workers (n=120,14.3%), other community members (n=105,12.5%), community meetings (n=59,7.0%), teachers (n=54,6.4%), friends (n=48,5.7%), religious leaders (n=47,5.6%), local leaders (n=31,3.7%) family (n=16,1.9%), newspapers and magazines (n=6,0.7%), and posters and printed materials (n=4,0.5%)

Caregivers of children without disability were further asked if they believe that community members in their area have adequate knowledge about children with disability to which a majority (n=342,83.8%) said no, and a few caregivers (n=66,16.2%) said yes. Similarly, more than three-quarters of caregivers of children with disability (n=656,78.2%) believe that community members did not have adequate knowledge about children with disability. Community members were reported to get information on disability from radio, teachers, religious leaders, fellow community members, community health/social workers, friends, family, mobile awareness creation caravans, newspapers, and printed posters. This finding suggests that more time and resources will need to be committed to sensitize community members on issues about disability.

Participants in five of the seven FGDs with male adults reported that community members have very limited knowledge of how to treat children WITH disability. However male adults in Kakuma and Kalobeyei reported that they had been trained by NGOs on the basics of handling children with disability. In one FGD a respondent noted that,

*'In one training session, we were trained that every child is entitled to an education regardless of whether they have disability or not. We were told that we should take all the children to school'*

Another male participant noted that,

*'We were also taught about the NCPWD, where children WITH disability are supposed to be registered and I think given an ID, that they use to get relief food and other assistance'*

All FGDs with female participants were in consensus that community members do not have adequate knowledge on how to treat or deal with children WITH disability and that they have not

been trained on the same. The participants further said that they were not aware of any laws that protect children WITH disability. Local chiefs and NGOs were the most mentioned sources of information for the community according to female participants in FGDs. Others were village elders, social workers, block leaders (within camps), local radio, village administrators, religious leaders, and teachers. The findings on sources of information were mirrored in feedback from male FGDs. All FGDs with BOM representatives reported that BOM members did not have adequate knowledge on how to care for and protect children with disability. They were also not aware of any laws that protect children with disability. NGOs, village administrators, churches, and local radio were mentioned as the main sources of information for BOM members.

On awareness of laws that protect children with disability, (n=344,84.3%) of caregivers of children WITHOUT disability were not aware of any. Only a small percentage (n=64,15.7%) knew of some laws. Some of the laws mentioned include the Kenya Constitution, the Children Act, and the Persons with Disabilities Act. About half of caregivers who were aware of these laws, (n=33,51.6%) said that the laws are being respected and (n=31,48.4%) were of a contrary view. A majority of caregivers of children WITH disability (n=732,87.3%) were unaware of any laws that protect children with disability, while (n=107,12.7%) were aware. These said that they were aware of the constitution of Kenya, the Children Act, and the Persons with Disability Act. More than half (n=61,57.0%), believe that the laws are respected, but (n=46,43.0%) were of a contrary view.

Caregivers of all children further opined on what could be changed or improved. Key among what they mentioned include access to a better environment, access to learning institutions, more teachers for children with special needs, assistive devices, protection of their rights, effective enforcement of relevant laws, training of caregivers, more health facilities, awareness creation on relative laws, enhanced integration of children with disability in ordinary schools, improved nutrition and diet, provision of recreation centers for children with disability, and general community sensitization on how to relate to children with disability.

### 3.7. Birth registration, and vaccination coverage

This section presents the extent of coverage of birth registration and vaccination for children with disabilities.

#### 3.7.1 Where the child was born

Caregivers were asked where their child was born, to which (n=448,52.0%) indicated a health facility. The other close to half (n=409,47.5%) reported that their child was born at home. A few did not know as they were foster caregivers. This is shown below. The findings affirm that still many children were born outside a health facility which could deny them the opportunity to receive the necessary early care and attention, including immunization.

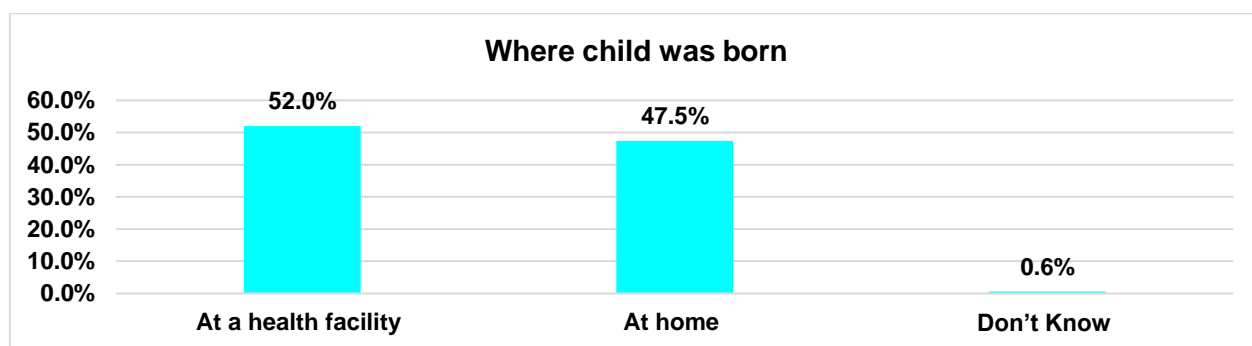


Figure 19: Where children with disability were born

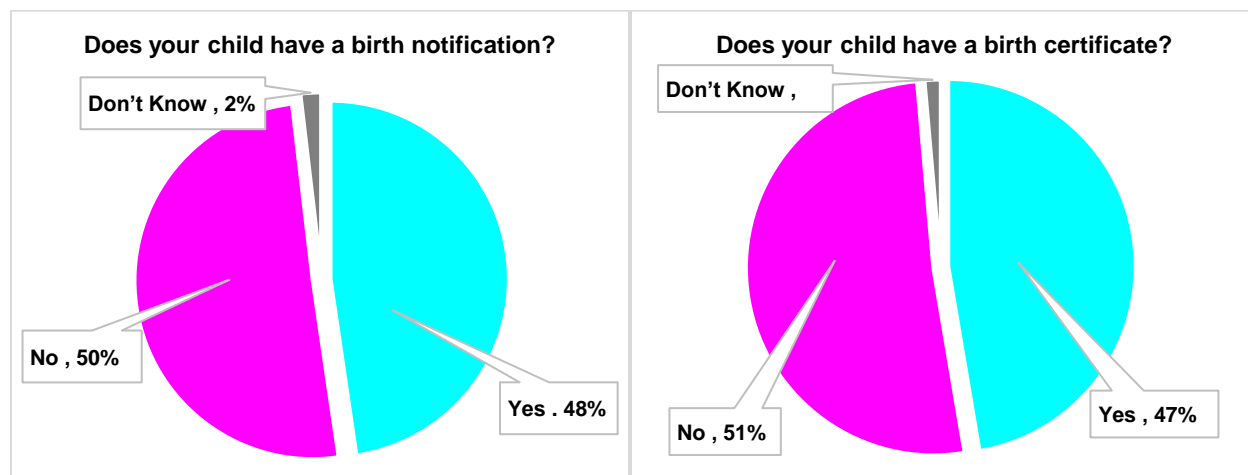
Across the wards, Letea ward had almost all caregivers (98.3%) reporting that their children were born at home. Overall close to half of all children were born at home as seen in the table below. This suggests that these births may not have been registered.

**Table 19: Where children with disability were born by ward**

Where was your CHILD born?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
At home	147	29	56	52	62	37	26	409
	45.0%	48.3%	98.3%	41.9%	44.3%	36.6%	49.1%	47.5%
Don't know	1	1	0	0	0	1	0	3
	0.3%	1.7%	0.0%	0.0%	0.0%	1.0%	0.0%	0.4%
N/A (Adopted/foster)	1	0	0	0	0	0	1	2
	0.3%	0.0%	0.0%	0.0%	0.0%	0.0%	1.9%	0.2%
At a health facility	178	30	1	72	78	63	26	448
	54.4%	50.0%	1.8%	58.1%	55.7%	62.4%	49.1%	52.0%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

**3.7.2 Birth notifications**

Half of the caregivers (n=435,50.5%) further reported that their children did not have birth notifications, compared to (n=411,47.7%) who had one. A small number (n=16,1.8%) did not know if the child had a birth notification. This finding was mirrored in the finding about the birth certificates to which (n=442,51.3%) of caregivers reported that their children did not have, while (n=408,47.3%) said that the children had birth certificates. A small number of caregivers (n=12,1.4%) did not know if the child had a birth certificate or not.



**Figure 20: Caregivers reporting that the child has a birth notification or birth certificate**

Across wards, the findings mirror those on where a child was born. In Letea ward for example where most children were born at home, a majority, 93% did not have a birth notification seen below

**Table 20: Children with a birth notification by ward**

Does Your CHILD have a birth notification?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
Don't know	2	1	0	0	2	1	10	16
	0.6%	1.7%	0.0%	0.0%	1.4%	1.0%	18.9%	1.9%
No	156	36	53	54	72	45	19	435
	47.7%	60.0%	93.0%	43.6%	51.4%	44.6%	35.9%	50.5%
Yes	169	23	4	70	66	55	24	411
	51.7%	38.3%	7.0%	56.5%	47.1%	54.5%	45.3%	47.7%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

### 3.7.3 Birth certificates

The presence of birth certificates was mirrored across the wards, with Letea ward topping with the number of caregivers (96.5%) reporting that their children did not have a birth certificate. Lack of the certificate denies these children access to core services such as NEMIS registration.

**Table 21: Children with a birth certificate by ward**

Does Your CHILD have a birth certificate?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
Don't know	1	1	0	0	0	1	9	12
	0.3%	1.7%	0.0%	0.0%	0.0%	1.0%	17.0%	1.4%
No	132	49	55	77	68	45	16	442
	40.4%	81.7%	96.5%	62.1%	48.6%	44.6%	30.2%	51.3%
Yes	194	10	2	47	72	55	28	408
	59.3%	16.7%	3.5%	37.9%	51.4%	54.5%	52.8%	47.3%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

Caregivers reporting that their child did not have a birth notification or certificate said that this was a result of the child being delivered at home, (n=266,44.6%), the registration center being too far (n=104,17.4%), do not know where to register (n=66,11.1%), did not find it necessary to register (n=45,7.5%), that the process was too complicated (n=62,10.4%), and that the cost of registration was high (n=46,7.7%).

### 3.7.4 Immunizations cards and immunization coverage

Furthermore, while (n=542,62.9%) of caregivers reported that their child had an immunization card, a significant (n=308,35.7%) reported to the contrary. Another (n=12,1.4%) did not know. Letea Ward had the highest number of caregivers (n=46,80.7%) reporting that their children did not have an immunization card. Nanaam ward similarly had more than half of the caregivers whose children did not have an immunization card as seen below. This suggests that tracking the vaccinations that children had received or the health progression of a child by service providers was a challenge.

**Table 22: Children with immunization cards by ward**

Does your child have an immunization card?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
Don't know	2	1	0	0	0	4	5	12
	0.6%	1.7%	0.0%	0.0%	0.0%	4.0%	9.4%	1.4%
No	83	22	46	46	41	53	17	308
	25.4%	36.7%	80.7%	37.1%	29.3%	52.5%	32.1%	35.7%
Yes	242	37	11	78	99	44	31	542
	74.0%	61.7%	19.3%	62.9%	70.7%	43.6%	58.5%	62.9%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

However, close to half of the caregivers (n=402,46.6%) said that their children were up to date on all immunizations. Close to a third (n=235,27.3%) said that most immunizations had been received, while another (n=124,14.4%) said the child had only received a few immunizations. While (n=80,9.3%) said that the child had received no immunizations, another (n=15,1.7%) said the child only received immunization at birth. This finding was consistent with the one on the availability of immunization cards seen above. Letea ward had the least full immunization coverage as reported by caregivers (n=8,14.0%) followed by Songot ward (n=12,22.6%).

**Table 23: Immunizations children with disability had received by ward**

Has Your CHILD received all appropriate immunizations to date?								
	Kakuma	Kalobeyei	Letea	Lokichogio	Lopur	Nanaam	Songot	Total
Completely up-to-date on all immunizations	172	43	8	41	75	51	12	402
	52.6%	71.7%	14.0%	33.1%	53.6%	50.5%	22.6%	46.6%
Don't know if the child has had immunizations	3	1	0	0	0	1	1	6
	0.9%	1.7%	0.0%	0.0%	0.0%	1.0%	1.9%	0.7%
Most immunizations have been done	95	9	8	52	35	21	15	235
	29.1%	15.0%	14.0%	41.9%	25.0%	20.8%	28.3%	27.3%
No immunizations have been done	10	1	37	0	8	19	5	80
	3.1%	1.7%	64.9%	0.0%	5.7%	18.8%	9.4%	9.3%
Only a few immunizations have been done	41	6	4	29	19	9	16	124
	12.5%	10.0%	7.0%	23.4%	13.6%	8.9%	30.2%	14.4%
Only at birth, none have been done since	6	0	0	2	3	0	4	15
	1.8%	0.0%	0.0%	1.6%	2.1%	0.0%	7.6%	1.7%
<b>Total</b>	<b>327</b>	<b>60</b>	<b>57</b>	<b>124</b>	<b>140</b>	<b>101</b>	<b>53</b>	<b>862</b>
	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>	<b>100.00</b>

A majority of caregivers were not supported with any nutritional plans for their child as reported by (n=706,81.9%). But (n=124,14.4%) reported that they received nutritional plan support for their child. They noted that this support came from a health facility (n=83,43.0%), NGO (n=38,19.7%), community health worker (n=22,11.4%), religious leader (n=10,5.2%), friend (n=15,7.8%) and traditional healer (n=5,2.6%).

### 3.8 Existing best practices for children WITH disabilities in schools and communities.

Identification of existing promising practices for children with disability was an uphill task in a community with a general deprivation of services and amenities for the larger community let alone children with disabilities. It is also important to note that a best practice does not necessarily mean that it was widely accessible, rather, it could also be that the best practice significantly contributes to improving the welfare of children with disability, wherever the practice was available, albeit with limited coverage.

Caregivers were asked their opinion on what worked best for children in school and in the community. Caregivers of children WITH disability mostly mentioned the school feeding programme (n=336,21.5%), followed by the presence of classes that are conducive for children WITH disabilities (n=233,14.9%) and supportive teachers who keep in touch with the caregivers (n=225,14.4%). Key informants and community members indicated that children received a meal in most schools in Turkana West Sub-county. Access to a conducive learning environment was however still limited in the sub-county.

Other mentioned services include trained teachers, health support programmes provided through the school, accommodative classmates, and psychosocial support services available in schools. The school feeding programme was similarly mentioned by more caregivers of children without disability (n=176,20.7%), followed by conducive classes (n=111,13.1%), health support programmes provided through school (n=108,12.7%), psychosocial support services in school (n=107,12.6%), and supportive teachers who keep in touch with caregivers (n=103,12.1%).

When it comes to home and the community, caregivers of children WITHOUT disability opined that the best thing for children with disability was an understanding and supportive community (n=188,27.3%), community health workers (n=108,15.7%), psychosocial support services for children and caregivers (n=94,13.7%), access to relevant health services (n=82,11.9%), cash transfer services from government (n=57,8.3%) and cash transfer services by NGOs (n=39,5.7%).

Discussions with key informants echoed the views of caregivers but also revealed additional practices that they nominated as best practices in the care and protection of children WITH disability. One of the practices is the **outreach programmes** to deliver health, vaccination, and registration services. Overall, the sub-county and the entire county face transportation challenges that bar children and their caregivers from accessing basic services. The outreaches take services closer to the people, effectively reaching a population that would otherwise not access basic services. They have also led to the registration of more children with the NCPWD. One key informant noted,

*'Most of these children are born at home, many are not registered at birth let alone with the NCPWD. They are therefore not able to access many services from organisations such as the NCPWD'*

While good in reaching the hard-to-reach population, outreach programmes were reported to be infrequent, and limited in geographical coverage and scope of conditions they can effectively address. They therefore heavily rely on referrals, which in most cases would be poorly equipped health facilities. Registration outreaches are similarly useful but they were noted to be limited in number and frequency.

Another practice identified as good was the **school feeding programme** implemented in almost all schools in the sub-county. The feeding programme was reported to be the main reason why children went to school. The assurance of a meal in school was a motivation for caregivers to send their children to school. Key informants observed that many children WITH disability, who were previously hidden in homes were increasingly being enrolled in schools. However, there

were many more children that were reported to be out of school who did not benefit from the feeding programme.

**Community health volunteers and social workers** were widely mentioned by both the caregivers of children WITH and WITHOUT disability, and by key informants as a good practice in the care and protection of children with disability. The community health workers move from house to house, supporting caregivers, children, and the larger community with their health needs. They are, in the process, able to assist caregivers in identifying disability and other health needs of children. This helps in the early detection of cases and in the continuous management of disability challenges, children face. Through Community Health Promoters (CHPs) and social workers, children WITH disability are consistently able to receive case-specific services and follow-up. They nevertheless face challenges related to transport, which limits the number of caregivers they can support. In addition, the nomadic nature of the community sometimes complicates the CHPs' work, when they are unable to find and follow-up with caregivers who migrate in search of pasture.

Key informants further echoed the need to **engage and involve individuals with disability** in the community in relevant activities and as role models. They for example noted how a local elected leader, who had disability and was a positive role model to other people and children in the community. In another example, a local teacher with sight difficulties was also a role model who many young people looked up to. Key informants called for the recognition and involvement of more people with disability from within the community in activities and community roles.

**Strengthening, and engaging Organisations of People with Disabilities (OPDs)** was also mentioned by key informants as a practice that needs to be encouraged. Borrowing from the saying that “the wearer of the shoe knows best where it pinches”, key informants noted that OPDs are best placed to champion the rights of people without disability. As such, their involvement in matters affecting children with disability was noted to be a good practice towards strengthening an agency for people with disability, which can then take up and own efforts to champion and advocate for the needs and rights of children with disability. There were notable efforts by partner organisations including Waldorf to actively engage OPDs in programme activities which ought to be encouraged.

Key informants further noted that the enactment of the **Turkana County Persons with Disability Act 2018**<sup>60</sup> by the Turkana County Assembly was a stepping stone and a significant step towards the inclusion of persons with disability in county development and other affairs. Among the provisions in Part III section 14 of the Act is for learning institutions to take into account the special needs of persons with disability, and for the establishment of special education institutions especially for the deaf, the blind, and those with mental difficulties. In section 15, the Act provides for the establishment, across all sub-counties, of an integrated system of special and non-formal education for persons with all forms of disabilities and the establishment, where possible of braille and recorded libraries for persons with visual disability. Key informants noted that while many of the provisions in the Act were yet to be implemented, the Act was a positive step towards institutionalizing inclusion in the county.

In addition to the legislation, there were social welfare officers and a board within the Turkana County government, who dealt specifically with matters of disability. The two county-level structures are well-placed to support the institutionalization of disability inclusion in the county policy, planning, and development programmes.

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<sup>60</sup> <http://kenyalaw.org/kl/fileadmin/pdfdownloads/Acts/TurkanaCountyPersonswithDisabilitiesAct2017.pdf>

Discussions with stakeholders in the education sector noted that the national government **capitation grants for Special Needs Education (SNE) learners** in special and integrated primary and secondary schools, were also a good practice in ensuring that a majority of special needs learners are enrolled in school. According to the status report on disability inclusion in Kenya 2021<sup>61</sup>, at the secondary level, the government disburses to special and integrated secondary schools an amount of Kenya Shilling (Kes) 57,974 per SNE learner per year. For primary education, the government allocates Kes. 3,720 for Free Primary Education for all learners with disabilities. Key informants noted that while this may not be adequate, especially in the context of Turkana West Sub County, it was a viable initiative that set a good basis for education inclusion in the sub-county.

On more operational matters, key informants lauded **networking efforts by the different development partners** in Turkana West Sub County to convene and share information on the different interventions that each of them was implementing. They observed that this may not necessarily eradicate all overlaps but it helps in collaboration and sharing of information among partners. If sustained, the networking could lead to more comprehensive coverage of interventions, reduce overlaps in the implementation of interventions, and increase the reach and impact of interventions by organisations supporting the care and protection of children with disability.

### 3.9 Challenges that affect children with disabilities; community, environment, and others.

Children with disability in Turkana West Sub-County were reported to experience a myriad of challenges. According to key informants, those living in the interior areas of the sub-county faced more challenging situations compared to those nearer the main towns, who had access to more amenities. Development interventions also tend to focus most of their attention on the easy-to-reach parts of the community, leaving the interior areas deprived of services and support<sup>62</sup>. Interviews with caregivers of children with disability revealed the challenges their children faced as seen in the table below. Access to an education that is relevant to the needs of these children topped the list of challenges mentioned. Others were mobility challenges, skilled health care, and social isolation.

**Table 24: Challenges children with disability face according to caregivers of children WITH disability**

<b>The most common challenges that children with disability in this community generally encounter as mentioned by caregivers of children WITH disability</b>	<b>Freq.</b>	<b>Percent</b>
Limited or no access to specialized education	636	22.7%
Accessibility and Mobility (accessing buildings, transportation)	566	20.2%
Access to skilled health care (facilities and personnel)	481	17.2%
Social isolation (not able to make friends)	431	15.4%
Mental health such as depression, and anxiety	378	13.5%
Stigmatization and discrimination	286	10.2%
Others specify	23	0.8%
<b>Total</b>	<b>2,801</b>	<b>100.00</b>

Caregivers of children WITHOUT disability similarly shared their views on the challenges that these children faced. Topping the list of challenges mentioned was the availability of schools followed by inadequate health services and lack of assistive devices. This is seen in the table below.

<sup>61</sup> <https://www.socialprotection.go.ke/sites/default/files/Downloads/STATUS-REPORT-ON-DISABILITY-INCLUSION-IN-KENYA-2021.pdf>

<sup>62</sup> Chambers, R. (1983). Rural Development: Putting the last first. London: Routledge.

**Table 25: Challenges children with disability face according to caregivers of children WITHOUT disability**

The most common challenges that children with disability in this community generally encounter as mentioned by caregivers of children WITHOUT disability	Freq.	Percent
Unavailability/inadequate special needs schools/learning	272	13.0%
Inaccessible/inadequate health services _ facilities and personnel _	250	11.9%
Lack of assistive equipment	233	11.1%
Mental health such as depression, anxiety	208	9.9%
Insufficient food and water	191	9.2%
Social isolation _ Not able to make friends _	176	8.4%
Discrimination in access to basic services _ education, health care, play spaces, etc. _	142	6.8%
Stigmatization by community members	138	6.6%
Transportation, mobility, and accessibility challenges	117	5.6%
Harsh environmental conditions	108	5.2%
Unskilled caregivers	90	4.3%
Ignorant community members	84	4.0%
Inadequate service providers _ health workers, disability specialists _	69	3.3%
Other Specify	13	0.6%
<b>Total</b>	<b>2,091</b>	<b>100.00</b>

Discussions with adult caregivers in FGDs also shed light on the challenges children WITH disability face. Bullying was mentioned in all seven FGDs with male adults, depression was mentioned in six FGDs, and isolation/discrimination in five FGDs, Other mentions were lack of disability-friendly schools, caregiver neglect, stigmatisation, children seen as a burden, lack of basic needs, lack of assistive devices, and lack of access to specialized treatment. Findings from FGDs with adult women mirrored those from the male community members, with bullying, depression, lack of basic needs, and lack of assistive devices as the most mentioned challenges.

Discussions with BOM representatives further noted that children with disability experienced high levels of loneliness. This was because of being isolated by other children and by their caregivers. Overall, they do not receive proper and relevant education, they have health issues partly due to lack of nutritional support and due to poor feeding habits, are stigmatized, and lack adequate psychosocial support as a result of which many suffer from depression and other social-emotional distress.

Multiple barriers and challenges were outlined by key informants we spoke to. These relate to culture, access to education and health services as well as social and economic. The barriers and challenges are discussed in more detail below.

### 3.9.1 Cultural Challenges.

According to key informants, negative attitudes and beliefs towards disability and people with disability were major challenges faced by children with disability. It was reported that many caregivers, parents, and relatives hide their children from the public. They argue that children with disability are cursed and, in some cases, they are thrown away in the bushes because they are associated with evil. Key informants noted that parents of children with disability fear stigma from the public which leads them to prefer to hide their children. They see the children as a source of shame that leads to stigma, discrimination, and isolation from their families, communities, and the larger society.

Key informants further noted that the community has a negative attitude towards the ability of children with disability, noting that they are not able to do many things including succeeding in formal education. As a result, children with disability are more likely to be married off early. In addition, the birth of a child with a disability sometimes leads to separation and divorce, which leaves the children mostly with their mothers. Furthermore, there are some traditional practices

and beliefs that may cause harm and neglect to children with disability including witchcraft, harmful rituals, and abandonment which, overall, expose children to risks of abuse, violence, and exploitation. Key informants reported that in some extreme cases, children born with a disability are thrown away because they are associated with evil or are seen as a curse. Most parents were reported to fear stigmatization.

On the contrary, livestock born with a disability was seen as a blessing and an indicator of good luck to the owner, who is believed would have plenty of livestock. These sentiments were echoed in discussions with female adults in FGDs. In one FGD, a participant reported;

*'I don't know if you know this, but animals with disability are considered as good luck. People believe that anyone with an animal that has a disability is likely to have plenty of animals. An animal with a disability was a sign of wealth or potential wealth'.*

Another participant in an FGD shared similar sentiments,

*'You will be surprised that people in this community value livestock more than children. For example, livestock born with a disability is seen as a blessing, while a child with a disability is seen as a curse. An animal with a disability is slaughtered and the blood is sprinkled on other animals as a way to spread the blessing'.*

Key informants further noted that children WITH disability face challenges associated with the pastoral way of life. This affects them in multiple ways. On one hand, when they are born away in the grazing fields they fail to get the most important medical attention and care, including early vaccination. On the other hand, even when children are born in health facilities and their homes, they are for various reasons unable to follow up with the necessary clinics leaving them susceptible to adverse health conditions.

### **3.9.2 Education-related challenges**

Challenges related to education mentioned by key informants include the lack of integrated schools in the Turkana West sub-county and the county at large. There was mention of only two integrated schools in the Katilu Ward, Turkana South sub-county, and Kakuma Ward in the Turkana West sub-county. There are two other private schools for children with hearing difficulties (St Lukes and St Bakhita) located in Lodwar. These are certainly not accessible to most children in Turkana including in the Turkana West sub-county due to long distances. The sub-county also experiences a shortage of skilled special needs education teachers, appropriate infrastructure, low transition rates, lack of or inadequate learning assistive devices such as braille, and high costs of learning. As a result, children WITH disability are either not enrolled in schools or those who are in school are not adequately facilitated to learn depending on their ability.

Key informants therefore mentioned that for most of the children WITH disability, school attendance allowed children to feed and pass the time. A key informant noted,

*You will be surprised that the only reason some caregivers have sent their children to school is so that they have access to a meal, often served to all children in school. In some areas only a few children, approximately 5% are in school, in Kakuma and Lodwar where schools are more and better then enrolment can be higher, say at around 60%.*

Key informants stated that some parents and caregivers are sceptical about sending their children to school. They fear for their children's safety while in school. Key informants noted that children WITH disability face the risk of being discriminated against, have few skilled teachers, coupled with the use of negative statements on the children, and schools generally have poor monitoring mechanisms for school attendance. Most schools lack inclusive spaces including classrooms and

playgrounds, while the cost associated with school attendance including uniforms, and transport for those not able to walk, simply keep children away from schools. Key informants further noted that children WITH disability in refugee camps have better access to relevant learning opportunities compared to those in the host community. This was largely due to support received from humanitarian agencies working within the camps.

Key informants called for inclusive approaches to education in the county, where schools take simple necessary steps, that are context-specific to allow children WITH disability to learn. They observed that some of the children only need teachers to, for example, adopt inclusive pedagogies such as speaking slowly and repeating what they have said to allow children to understand. Others could be the use of class assistants as necessary. They also called on teachers to make an effort to learn inclusive approaches to teaching, however basic, to better include children WITH disability in their lessons. This could for example mean the use of sign language. They further called on the national and county governments to invest more in school infrastructure to allow learning by children with disabilities.

### 3.9.3 Health-related challenges

Among the most mentioned challenges related to health were the **migration of caregivers** and **access to specialized health services** for children WITH disability. Discussions with key informants highlighted the migration challenge which prevents caregivers and children from accessing the necessary health services, when away from their homes in search of pasture. As a result, women deliver in their homes, and many children fail to or delay accessing health services including vaccinations. Discussions with health officials indicate that this could lead to birth and health complications. They however further noted that while most mothers do not move as much as the men do, it becomes difficult for them to take their children to clinics, especially in times of drought. Furthermore, it was difficult for them to carry children to health facilities as they grew older and heavier, making access to healthcare by children and generally by people with disability difficult.

Key informants further reported that caregivers often **shy away from vaccinations** due to side effects. Often vaccinations lead to increased body temperature, which often leads to body fever that can last for a couple of hours, in a relatively hot environment. This, alongside limitations in physical access to health services, health officials estimate that just about 40% of children are fully vaccinated. Besides limited access to specialised health care, **community-based rehabilitation centers** were reported to have closed due to a shortage of funds to run them. Most of the child assessments by organisations including the Kenya Red Cross (KRC) and International Rescue Committee (IRC) are done in schools meaning **children not in school may not be benefiting from these assessments**, and therefore they miss out on individualised care and support.

The **capacity to undertake functional assessments among** organisations implementing programs targeting children with disability was also brought into focus. Key informants echoed the need for organisations to build their capacity in undertaking functional assessments, to better inform the nature of care and support children need. They noted that organisational staff and other service providers who interact with children, such as teachers, Community Health Promoters (CHPs), counsellors, and medical personnel should have the capacity to carry out functional assessments either through, observations, interviews, tests, or questionnaires, as may be appropriate in each context. A key informant noted,

*'Without a functional assessment, one cannot for sure know a child's strengths and challenges and they cannot therefore offer support that will be specific to the needs of that child. Service providers such as teachers and community health workers*

*should be knowledgeable on basic functional assessment to better respond to the needs of children with disability...'*

As a result of the challenges related to access to health facilities, many children with disability were reported to be **unregistered**, with the Registrar of Births and with the NCPWD. These findings were echoed in interviews with caregivers 92% of whom reported that children WITH disability were not registered with an organisation of people with disability, 50% did not have a birth notification and 51% did not have a birth certificate. A lack of these legal documents may prevent children WITH disability from accessing key government services and support, such as National Education Management Information System (NEMIS) registration. Key informants further reported that most caregivers were not aware of the benefits of registration. For example, a key informant reported that some caregivers did not know the difference between NCPWD and the National Hospital Insurance Fund (NHIF).

While findings from caregivers show that most **children did not have nutritional plans**, key informants indicated that nutritional planning was difficult to achieve in the Turkana West sub-county and the larger part of the county. This was because of a shortage of food varieties and water which makes feeding patterns rather unpredictable. As a result, caregivers are only sensitised to the combination of foods that they should give to their children.

Another health-related challenge has to do with **dilapidated and broken-down health equipment**. Key informants for example reported that many health facilities had faulty fridges, meaning that the storage of vaccines and medicine remains a challenge. In addition, without functional and more efficient equipment, the diagnostic capacity in most health facilities remained limited, meaning the management of children WITH disability was not necessarily informed by accurate diagnosis and data. **Shortage and lack of medicine** in public health facilities were also reported as a challenge, yet many caregivers lacked the financial capability to purchase medicine from private chemists, or the ability to walk long distances where private chemists and clinics are located. As a result, key informants indicated that caregivers tend to rely more on traditional medicine.

Key informants further noted that while the health system in the Turkana West sub-county is significantly complemented by the CHPs, there is a challenge of **weak and fragmented referral and reverse referral systems** to support the work of the CHPs. In addition, **health personnel were reported to be few, and most of them concentrated in the main urban centers**. According to key informants, health **facilities are not well distributed** across the sub-county and the county at large, with, for example, functional and specialized clinics located only in Lodwar. Overall, the health system was noted to be weak, remote, paucity, and fragmented.

#### 3.9.4 Socio-economic challenges

According to key informants, the most significant socio-economic challenge was the **harsh climatic and economic conditions** the people of Turkana West and the larger Turkana faced. In the largely arid semi-arid area, economic opportunities for residents of the sub-county were limited while the weather conditions were mostly very hot. The main economic activity is pastoralism. Animals are heavily affected by changes in weather conditions, leading to death and therefore massive losses to the community. Key informants noted that the community suffers food insecurity and water shortage, which complicates the feeding and health status of children.

According to reports by the UNHCR and the World Bank (2021<sup>63</sup>), **low incomes** of both refugee and host communities are associated with **high poverty levels** in Turkana West. According to UNHCR and World Bank (2021), “68 percent of refugees in Kakuma and 72 percent of Turkana hosts are poor, and both populations are highly **food insecure**”. Data from the Kenya Poverty Reports (2023)<sup>64</sup>, shows Turkana has relatively high rates of food poverty<sup>65</sup>, overall or absolute poverty<sup>66</sup>, and hardcore poverty<sup>67</sup>. The report shows that 63.4% of people in Turkana were food-poor, 77.7% were in absolute poverty and 45.7% experienced hardcore poverty. Compared to national statistics, 30.5% of the population is food-poor, 38.6% are in absolute poverty, and 5.8% experienced hardcore poverty. Key informants noted that overall, the high poverty levels increased the vulnerability of children, especially those WITH disability.

The **pastoral way of life** creates an additional burden for children WITH disability. Many pastoral households often face challenges accessing key services and following up on health-related programmes and schools. As mentioned earlier, it is even more challenging for children born when the caregivers are on the move, in search of pasture. They, for example, miss out on the initial vaccinations and or are unable to follow up on post-natal clinics. They also delay or miss out on registering their children with the registrar of persons. Late registration was noted by key informants to be a lengthy process that can be costly. Many caregivers find it difficult to follow up on late registrations. Migration also leads to school dropout among some children who follow their parents in search of pasture. One key informant noted,

*‘When caregivers move in search of pasture, at times they move with their children. This means that if a CHV had left a family in one location, they may not find them there the next time they visit. When they move too far away accessing health services is a challenge. Children will also most likely stop attending school to follow their parents...’.*

Key informants further observed that overall, **children in refugee communities had more and better services compared to those in the host community**. This was because of the multiple numbers of organisations and interventions in the refugee community as compared to the host community. According to key informants, this means that overall, a child WITH disability, located in the refugee camps was more likely to have much easier access to key services compared to a similar child in the host community. A key informant noted,

*‘The refugees have a better life than the host community, they have all the services they need there including schools and health facilities. Most of the NGOs are working in the refugee camps. Refugees are well taken care of, not like the host community...’.*

Another challenge mentioned by key informants was the poor infrastructure in Turkana in general and the **lack of disability-friendly infrastructure for children with disability**. Except for the main urban areas of Lodwar, Kakuma, Lokichar, and Lokichogio which have good road networks, along the main roads, other parts of Turkana West Sub County and the wider Turkana have poor road network which prevents easy movement of goods, and people including service providers.

<sup>63</sup> <https://reliefweb.int/sites/reliefweb.int/files/resources/Understanding-the-Socio-Economic-Conditions-of-Refugees-in-Kenya-Volume-B-Kakuma-Camp-Results-from-the-2019-Kakuma-Socioeconomic-Survey.pdf>

<sup>64</sup> <https://www.knbs.or.ke/publications/>

<sup>65</sup> **Food poverty:** Individuals (or households if estimated at household level) whose **food consumption** per adult equivalent was less than KSh 2,331 per month in rural areas and KSh 2,905 per month in urban areas, respectively, were considered to be food poor or live in “food poverty”.

<sup>66</sup> **Overall (absolute) poverty:** Individuals (or households if estimated at household level) whose total consumption per adult equivalent was less than KSh 3,947 per month in rural areas and less than KSh 7,193 per month in urban areas, respectively, were considered to be overall poor or live in “overall poverty”

<sup>67</sup> **Hardcore (extreme) poverty:** Individuals (or households if estimated at household level) whose **total consumption** per adult equivalent was less than KSh 2,331 per month in rural areas and less than KSh 2,905 per month in urban areas, respectively, are considered to be hardcore poor or live in “hardcore poverty”.

Mothers particularly face challenges when they develop complications during delivery, and they cannot easily access a health facility. Availability of means of transport was also reported to be a challenge. A key informant for example noted;

*'We have lost many mothers who develop complications during delivery and are unable to access a health facility. You never know if some of the complications that mothers go through during delivery could be the reason for some forms of disability*

The **sustainability of interventions** was similarly mentioned as a challenge that children with disability face in Turkana West. Key informants noted that NGOs support different interventions for children with disability including education support and health support programmes. However, these programmes are not sustained when NGO programmes come to an end, in which case the gains made tend to be reserved. Health care was noted to be one of the most affected by the pull-out of NGOs. Children who receive consistent health support from NGOs often have challenges when the NGOs close their programmes due to accessibility and cost of specialised health care. Key informants echoed the need to integrate the government and local organisations into the NGOs-funded programmes, to build their capacity for continuity.

Related to this was the **shortage of funding to support programmes** targeted at children with disability. Key informants noted that programme funding was on the decline, a situation that affected the quantity and quality of programmes in the Turkana West sub-county. Partners are unable to carry out comprehensive programmes that address the unique and diverse needs of children based on their disability. On the contrary, they tend to emphasize core cross-cutting interventions that benefit a majority of children with disability. Even though, key informants noted that the programme focus was narrow and short-lived.

The other challenge mentioned by key informants was that of **weak social support programmes** within the community. Given the community's pastoral nature, the formation of social support groups for caregivers of children with disability is limited. Caregivers of children with disability lack adequate forums where they can unwind, and share experiences, and knowledge about disability. They rely on the information they receive from the health facilities for those able to access health facilities, information shared by CHPs, and their individual experiences. According to key informants, this was the reason why the care of children with disability was very different across caregivers. They called for the formation and support of local social support groups where caregivers of children WITH disability can share their experiences. The groups will also help monitor disability issues and care of children WITH disability within their areas.

#### 4. SUMMARY, CONCLUSION, AND RECOMMENDATION

Findings from this study bring to light the burden of caregiving that caregivers of children WITH disability bear in Turkana West County. Children experienced varied difficulties across all the levels of the Child Functionality Module (CFM). In addition, findings show that access to critical equipment and basic services for children WITH disability was limited, leaving the children and their caregivers struggling as they navigate through their day-to-day activities.

Findings further show that children with disability face a myriad of challenges in accessing education and health services. In education, approximately two-thirds of the children were enrolled in schools. A majority of them were in ordinary schools that were neither equipped with the necessary equipment nor with skilled teachers to attend to the special needs of children with disabilities. Besides, negative attitudes towards education have seen many caregivers opt not to enrol their children in schools, while others expressed concerns over the safety of their children when in school. In health, caregivers and children with disability face difficulties accessing available health facilities. Furthermore, most of the existing health facilities were inadequately equipped and had limited capacity to attend to the special needs of children WITH disabilities. As a result, many caregivers prefer to seek health care from traditional herbalists. Health care was at best remote, fragmented, and paucity.

The psychosocial and safety support system in the sub-county was insufficient and stressed and therefore unable to effectively support the care and protection of children with disabilities. This was compounded by a negative attitude towards people and children with disability among community members, some of them referring to children with disability as a curse and a bad omen. Registration of children with disability at birth and with OPDs including NCPWD, was yet to reach close to half of the children, effectively preventing them from accessing critical and essential services including access to NEMIS

This notwithstanding, a few good practices were reported including, the school feeding programme which pulls and keeps children enrolled in schools, CHPs, and social workers who made frequent home visits to households of children with disability, engagement of people with disability in community activities including leadership positions and as teachers, which motivated children with disability, the County Persons with Disability Act 2018, which sets the basis for the care and protection of people with disability in the county, social welfare officers and a board within the Turkana County government, who deal specifically with matters disability, and the capitation grants for special needs education learners which support their education.

From the findings, this study puts forth some recommendations, which could contribute to improving the situation of children with disability in Turkana West Sub County and Turkana County as a whole.

1. **Awareness creation:** The national and county governments and other development actors may need to invest more time and resources in sensitizing the community on issues about disability. The study revealed that high levels of misconceptions and misunderstanding on disability, which if addressed could lead to improved care and protection of children with disability.
2. **Build Capacity for Functional Assessments-** Organisations intervening in disability issues ought to focus on building and enhancing the capacity of front-line caregivers, including parents and other caregivers, teachers, CHPs, and social workers to conduct functional assessments for children WITH disability. Functional assessments are the very first step in determining the treatment, care management, and education pathway of a child with disability.
3. **Enhance and support outreach programmes:** The government and development partners ought to enhance and promote community outreach programmes. These were

reported to be effective in reaching the hard-to-reach populations. When they are complemented by referrals and reverse referrals, they benefit many more children, otherwise unable to reach the health facilities. More outreach programmes in number, scope, and frequency should be supported, and designed to cover the special needs of children with disability, registration, and general health screening among others.

4. **Ensure appropriate timing for screening of children.** Partners, and other agencies involved in screening children for disability might by design target most of the screening to take place when there is pasture (considering most of these communities are pastoralists and nomads) and when most households are settled in their homes. This will likely lead to more children being screened.
5. **Strengthen coordination among organisations in Turkana West Sub-County to strengthen the referral system.** While multiple organisations were actively intervening on issues around disability in Turkana West Sub-County and largely in the refugee communities, many tend to work in silos, save for occasional networking meetings where they only shared updates on what each organization did. This, unfortunately, seldom influenced the choice of interventions across the organizations. Closer coordination of actors might lead to more impact from interventions. Besides, this may also strengthen the referral system within Turkana West Sub County if a clear pathway could be mapped showing which organisation did what and where. Within the camps, this can be championed by UNHCR, in collaboration with the (national and County governments) Department of Children Service (DCS), while the DCS could champion the same across the host communities.
6. **Existing and new infrastructure should be disability friendly.** The county government may, in line with the provisions of the Persons with Disability Act ensure that the existing and upcoming infrastructure especially in schools, are disability friendly to improve access, retention, and transition for children with disability. For any new developments, for example, the county government should target construction plans and approvals to ensure that they are inclusive and disability friendly. Existing infrastructure should similarly be renovated to make them disability friendly, and hence offer reasonable accommodation and access.
7. **Invest in solar energy to power learning and health facility equipment:** The national and county governments ought to plan and support the installation and maintenance of solar power in schools and health facilities to ensure the uninterrupted running of key equipment necessary for the care and protection of children with disability. With power supply reported to be erratic and costly, health facilities often go for days without power which affects the shelf life of drugs including vaccinations. Education institutions on the other hand lack power that can support the use of modern technology that can support learning by children with disability.
8. **Educate caregivers on self-care and caring for children with disability.** Organisations working with households for children with disability ought to prioritize educating children on self-care. Caregivers were reported to face numerous challenges including stigma from other community members. This takes a toll on the caregivers which often causes some of them to hide their children from the public. Skills on, for example, self-acceptance and how to care for children with disability would help them to cope.
9. **Lobby for the linking of the NCPWD database with the Child Protection Information Management System (CPIMS)** to improve child protection data for children with disability. The government may explore this possibility with Turkana West sub-county as a pilot. This will aid in the collection of timely and up-to-date data on children with disability.
10. **Teachers ought to be trained and encouraged to apply inclusive pedagogies when teaching.** Adoption of simple inclusive pedagogies such as speaking slowly while teaching might go a long way in ensuring children with disability and other learning difficulties are not left behind in learning. Capacity building for teachers supported by programme partners may therefore aim to equip teachers with skills that can enable them to integrate methods that enhance learning by children with disabilities during their lessons.

11. **Support local organisations of people with disability to enable them to complement the work done by organisations intervening in disability issues.** Organisations for people with disability have the best chance to champion the rights of people with disability. The focus for organisations, therefore, ought to be on building an agency for people with disability and supporting them to champion the rights of children and adults with disability.
12. **Involve more people with disability in community activities including leadership:** People with disability who perform critical roles such as teachers, doctors, counsellors elected leaders are normally seen as role models for children with disability. This ought to be encouraged by governments and development organisations, to give children with disability hope.
13. **Consider more investments in CHPs and Social workers.** In an environment with a poor transportation network, caregivers of children with disability relied more on CHPs, and social workers for most information on the care and protection of children with disability. CHPs and social workers can easily reach out to more households and disseminate relevant information. CHPs are also a strategic avenue for the collection of timely and accurate data on disability in the sub-county.
14. **Support the establishment and strengthening of social support groups for caregivers.** These have the potential to provide mutual support, connection, knowledge, and experience-sharing opportunities for caregivers of children with disability
15. **There is a need for further research.** More research is needed to gather similar data for all other sub-counties in Turkana County. In addition, a deeper understanding of the socio-economic factors and how they impact disability would be essential in designing long-term disability support programmes in Turkana County.

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**ANNEXES**

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06.06.23\_Translated\_  
TOOL A WITH CWD\_I



06.06.23  
Translated\_TOOL B W



Translated\_TOOL  
D\_FGD Guide for Adu



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G\_FGD Guide for CHIL



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