

Childhood Disability and Malnutrition in Turkana Kenya

A Summary Report for Stakeholders and Policy



This study was funded by CBM and was conducted in partnership between: Kenyan Red Cross Society; CBM East Africa Regional Office; International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine

KRC: James Kisia , Victoria Mwenda, Velma Nyapera, David Otieno and Hellen Mwangovya

CBM: David Munyendo and Kirstin Bostelmann

LSHTM: Maria Zuurmond, Severine Frison, Hannah Kuper and Jenny Evans

Study Background

There are approximately 93 million children aged 0-14 years living with "moderate or severe disability".[1] This equates to one in twenty children globally (5.1%). Childhood disability is most common in the poorest parts of the world. [1, 2]

Malnutrition is a leading cause of childhood death in these low income settings, causing almost half of child deaths in 2011. [3] Malnutrition may also be linked to childhood disability (Figure 1). Childhood disability is important, because malnutrition may further increase morbidity and mortality among children with disabilities. Few studies have addressed the relationship between disability and malnutrition. [4-7]

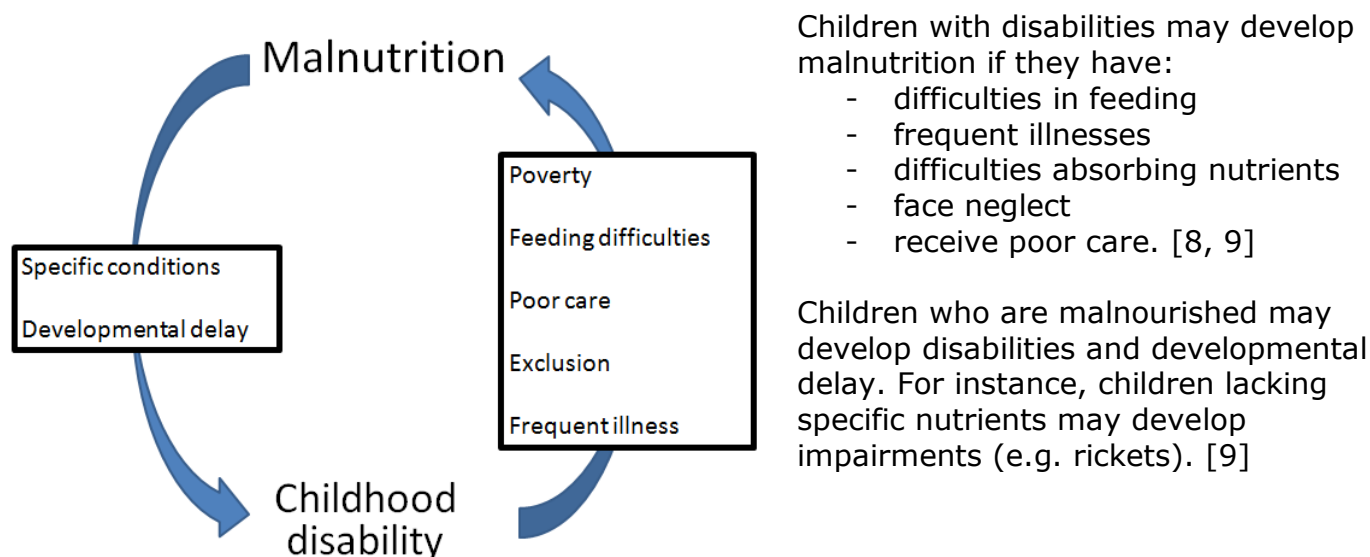


Figure 1: Potential pathways between malnutrition and childhood disability

Children with disabilities may be particularly vulnerable to malnutrition during humanitarian crises. This is because access to basic resources substantially reduces in these times.[10] Humanitarian aid may be less accessible for children with disabilities and their households. One such region is Turkana County within the Rift Valley province of Kenya. This region has been repeatedly classified as experiencing a humanitarian emergency (level 4) under the Integrated Food Security Humanitarian Phase Classification (IPC).[11]

The aim of the study was to assess whether children with disabilities were included within humanitarian and food security response programmes in Turkana, and whether there is an association between disability and malnutrition.

This question was explored through qualitative and quantitative studies.

METHODS

The focus of the research was the Turkana Central and Loima districts. The fieldwork was undertaken in 2013 through a combination of qualitative research and a population based case-control study.

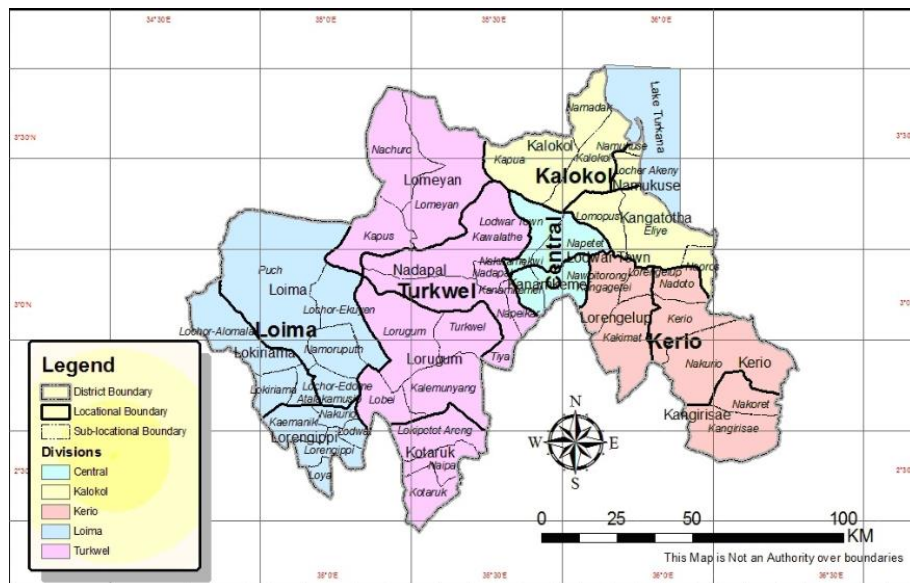


Figure 2. Turkana Central District Administrative Boundaries



Figure 3. The field team for the quantitative study

Ethics

The following measures were taken to accord with ethical standards:

- Written informed consent was obtained from the primary caregiver of each child
- A family member was present during the examination of each child.
- Ethical approval from Institutional Research and Ethics Committees from Moi Teaching and Referral Hospital in Kenya and LSHTM
- Children with disabilities or malnutrition requiring services were referred as appropriate

Qualitative study

The qualitative research was undertaken in April/May 2013 in Turkana Central. Two interviewers and two translators undertook the research.

In-depth face to face interviews were undertaken with 31 families of children with a range of disabilities, using an interview guide. Children with disabilities aged 10 years and under were identified from existing KCRS supported projects and from additional information gathered through local community health workers and KCRS volunteers. They were sampled from across four sub-locations which reflected different livelihood zones. A total of 23 villages were covered, the sample included both boys and girls, and included children with a range of different types of impairments (physical, hearing, visual and intellectual impairments).

Most interviews were in the local language Turkana, and some in Kiswahili. Detailed notes were taken during the interviews. All interviews were recorded and transcribed into English. Most interviews took place at the child's home. The interview guide covered the following topic areas:

1. Basic information on the family
2. Beliefs and attitudes about the child's condition
3. The impact of caring for a child with a disability
4. Feeding practices
5. Access to services (health, education, humanitarian and nutrition programmes)

In addition, ten interviews and small group discussions were undertaken with 16 key informants.

Qualitative data analysis

A thematic analysis was conducted. Some a-priori codes were identified from existing literature. Both interviewers separately identified a list of key themes and sub-themes, and these were then synthesised to provide an initial framework for analysis. Further sub-themes emerged during the data analysis process. The interviews were analysed using specialist software for qualitative data collection (NVIVO) and final coding and analysis was undertaken at LSHTM. for qualitative data collection.



A grandmother with her grandson with a disability

Quantitative study

Summary: For the quantitative study we selected children with disabilities (case), their closest age sibling (sibling control) and their closest age neighbour (neighbour control). These children underwent anthropometric measurement and their parents completed a detailed questionnaire.

The quantitative research field work was undertaken in July/August 2013.

Selection of children with disabilities

Children with moderate/severe disabilities in the community aged 6 months to 10 years were identified through key informants.

Key informants in the community were identified (community health workers, Kenyan Red Cross Volunteers, representatives from disabled people's organisations). The key informants underwent 1 day of training about childhood disability. They then returned to their village and identified children who potentially had a disability during the following 2-3 weeks.

A paediatrician and an interviewer visited the potential cases identified by the key informants to ascertain as to whether or not the child had a moderate/severe impairment. The child was assessed using a questionnaire (Washington Group-UNICEF childhood disability questionnaire) and the paediatrician then examined the child to confirm the type and cause of impairment as well as rehabilitation and medical needs.

The types of impairment included:

- Physical impairment (physical examination)
- Epilepsy (questionnaire)
- Visual impairment (visual acuity assessment)
- Hearing impairment (questions, response to noise, examination with otoscope)
- Intellectual impairment (professional opinion of paediatrician).

Selection of control subjects

Two control subjects were selected for each child with disability (case):

- Neighbour control: child nearest in age living closest to the child with a disability and preferentially of the same sex.
- Sibling control: sibling living in the same household as the case and whose age was closest to that of the case.

The purpose of two controls was to separate out the potential impact of disability on the lives of children due to their poverty (i.e. in comparison to neighbour controls) or purely in relation to the disability (i.e. in comparison to sibling controls).

We verified that the controls did not have disabilities through administering the Washington Group-UNICEF questionnaire and through examination by the paediatrician.

Data collection

The caregiver of the case and controls were interviewed using a semi-structured questionnaire. The children's anthropometric measures were taken by trained field researchers.

The interviews included questions on:

- Household poverty
- Education of the child
- Health of the child
- Foods consumed regularly
- Feeding difficulties
- Receipt of humanitarian aid

The following measurements were taken for each child: Weight

- Height/length
- Mid Upper Arm Circumference (MUAC)
- Arm length
- Tibia Length



Anthropometric measurements taken on a child in the study

Training of field staff and pilot study

The questionnaires were pilot tested and translated into Ng'aturkana. There was a structured training programme for the interviewers, paediatrician and anthropometry team, that included theory and practice sessions.

Data analysis

Double data entry, range and consistency checks were undertaken in Kenya. All statistical analyses were undertaken using Stata version 12 (StataCorp, Texas).

Statistical analysis included simple descriptive tabulations that compared cases with neighbourhood and household controls. Furthermore, calculations of mean differences and odds ratios with 95% confidence intervals were done. Additionally, multivariable logistic and linear regression analyses to estimate the relationship between disability and anthropometry, socio-demographic characteristics, including age, gender, and poverty markers was carried out.

The nutritional status of the children was compared to the WHO Child Growth Standards, by calculating standard deviation scores ("z-scores") using Stata macros for weight for age, height for age, weight for height (for children 5 years and younger) and body mass index (BMI) for age. [12] Children with z-score values outside the recommended range (z-scores greater than 5 or 6/less than -5 or -6, depending on the measure) and defined "under height for age", "under weight for age" "under BMI for age" as a z-score of -2 or less were excluded.

RESULTS

Study sample:

The case-control study included 311 children with disabilities, 196 Sibling controls and 300 neighbour controls (Table 1). It was not always possible to identify sibling controls in the correct age group.

The average age of the cases was 2.8 years, and two thirds were boys. The cases and controls were similar in terms of age and gender.

Table 1: Characteristics of children with disabilities and controls

	Child with disabilities N=311	Sibling control N=196	Neighbour control N=300
Sex	Male 201 (65%)	107 (57%)	177 (60%)
	Female 109 (35%)	80 (43%)	118 (40%)
Age	6 months-<2 26 (9%)	22 (12%)	26 (9%)
	2-4 96 (31%)	72 (38%)	101 (34%)
	5-7 114 (37%)	64 (34%)	215 (42%)
	8-10 70 (23%)	33 (17%)	48 (16%)
Mean Age	2.8 (0.9)	2.6 (0.9)	2.7 (0.9)

The qualitative research included 31 families with 36 children with disabilities. Physical disabilities were most common, and six children had a probable diagnosis of cerebral palsy. Five children had a developmental delay/intellectual disability. Two children had an identified sensory impairment (one child complete blind and one child with partial deafness).



A child with disabilities sheltering from the sun

Prevalence, type and cause of impairment

The key informants identified 311 children with moderate/severe disabilities.

Estimation of prevalence of childhood disability: There are an estimated 41,674 children aged <10 years living in Turkana Central and Loima. [13] This gives a minimum prevalence of moderate/severe disability in children of $311/41,674 = 0.75\%$ (0.66-0.83%).

The 311 children with disabilities had 321 diagnoses (some had multiple impairments).

The largest impairment group was physical impairment (n=172, 42%), among whom 31% had cerebral palsy, 14% had rickets and 10% had muscular dystrophy. Intellectual impairment was responsible for 22% of diagnoses (n=88), and included 20 children with Down's syndrome. The majority of the remaining children were not diagnosed with a specific condition. Epilepsy, hearing impairment and visual impairment were less common.

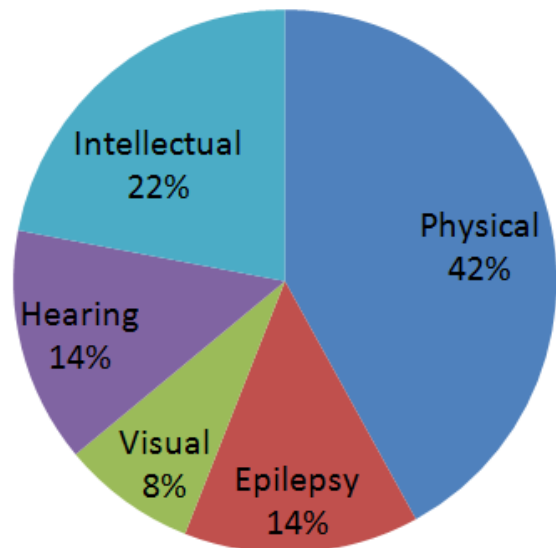


Figure 1: Types of impairments

Cause of impairment

The paediatrician reported the apparent cause of disability for 267 children as: congenital (67%), illness (13%), birth (6%) and trauma (5%).

The qualitative study explored beliefs and attitudes about the child's condition There were very low levels of understanding amongst caregivers about their child's impairment. Commonly caregivers held multiple parallel views to explain the cause of the disability, and most frequently they explained that it was due to a curse or bad spirit or God's will.

A small group of parents identified a medical reason for the disability and in some communities close to Lake Turkana, local environmental factors, such as the water or the soil, were used to explain the child's condition.

"It is believed that there is someone in the family who is unhappy with my family so he punishes them through the child."

"I used to faint before I gave birth. The traditional healer told me that the fainting was as a result of a curse from my parents. My parents cursed me because I married a man whom they didn't want me to marry."

"It is God that made him blind- it's something that befell him from God or from the Devil.....the Devil chooses who he wants to be blind or to be paralysed."

Access to treatment, rehabilitation and attitudes towards disability

Only 46 of the 311 children with disabilities had ever received rehabilitation (15%). Barriers to treatment were cited as: lack of awareness (34%), lack of money (33%), lack of perceived need (18%) or lack of transport (4%).

The qualitative study showed very similar findings. For most cases the caregivers had not sought any medical diagnosis, although it was common to seek treatment from traditional healers.

Caregivers frequently described struggling to carry their child to the health services, which was difficult as they grew bigger. Some of the children had problems with incontinence or with behavioural difficulties, and this was a further complicating factor.

Even where they had been to a hospital or clinic, there was considerable confusion about the nature of their child's condition, a lack of information about the cause and options for treatment.

Another key barrier to treatment was a lack of information about available and of referral pathways amongst the families and the health professionals at the community level. There was a lack of treatment and rehabilitation services available. This results in the need for families to travel long distances, with the associated opportunity costs.

Many families talked about the stigma and shame of having a child with a disability. Some children with disabilities were seen as a burden as they could not help with household chores or would not bring in a dowry. Most key informants said that children with disabilities were hidden away at home. There was some evidence of neglect of children with disabilities.

SUPPORTING QUOTES

"I have been considering taking him to the hospital but I have no faith that anything can be done medically about this disease; it is caused by the environment"

"We preferred seeking help from a traditional healer instead of the hospital on advice from the villagers who felt that there are some diseases which can be treated at home, such as polio."

"In the past we took him for physiotherapy..... we would hire people with bikes and would sit him in the middle and take him.[Why did you stop going?] The main reason was the child was too heavy to take, and we had no means of carrying him "

"This child was born with this condition [club foot]. We took her to the hospital in Kitale, and they put a plaster on her leg. We were supposed to go back to hospital for treatment but we have not taken her there because we do not have money."

"I do not think A is alive. I am just taking care of him until his final death."

"Some in the community are merciful. Others say 'Why is she carrying a dead person...a useless person'"

"I do not think that this child is of benefit to the family in any way.... She can't get married or help with household chores."

Socio-demographic characteristics and childhood disability

Children with disabilities were significantly more likely to have a female head of household, compared to neighbour children without disabilities (Table 2).

Other household measures were not related to childhood disability (education of the household head or spouse, polygamous family, nomadic family, socio-economic markers, household size, number of children per household, livelihood, water and sanitation). This pattern suggests a lack of relationship between poverty and childhood disability in this region.

Table 2: Socio-demographic characteristics and childhood disability

		Child with disabilities	Neighbour control	Age and sex adjusted Odds Ratio (95% CI)
Head of household	Adult male	250 (84%)	262 (90%)	Baseline
	Adult female	46 (16%)	26 (9%)	1.9 (1.1-3.2)

Understanding Odds Ratios: An **odds ratio** (OR) shows association between an exposure and an outcome. In this example, between head of household (exposure) and whether the child has a disability (outcome). The OR represents the **odds** that an outcome will occur given a particular exposure, compared to the **odds** of the outcome occurring in the absence of that exposure. As an example:

- Odds of disability for a child living in a family headed by a man = $250/262=0.95$.
- Odds of disability for a child living in a family headed by a woman is $46/26=1.77$
- Odds ratio = $0.95/1.77 = 1.9$. This means that child is almost twice as likely to have a disability if he/she lives in a house headed by a woman, rather than a man.

The 95% confidence interval shows the range of odds ratios that are likely, with 95% probability. If the confidence interval does not include 1, then the odds ratio is statistically significant (as in the example given above).

The qualitative study mirrored these findings. Half of the households were single parent households which were female- headed. Fathers had died, left, or were permanently working away from home. In other instances the husband visited rarely and irregularly. The parents commonly described how their caring role limited their ability to undertake livelihood activities, so that it is surprising that no link with poverty was shown in the quantitative study.

"I am not able to do any work here all day. I have to carry the child all through the day. I am not able to make as many mats as other women make. I only make one mat every month while other women make even 5 mats. Sometimes I am not able to make any mat at all."

"I have to stay home to take care of the disabled child, I am not able to engage in any activity that can help me get income."

Education and childhood disability

Children with disabilities (aged 5+) were significantly less likely to attend school than neighbour controls (Table 3). Among children who did attend school, children with disabilities were at significantly lower levels in the education system, but did not appear to be more likely to miss days of school.

Enrolment in school varied by impairment type. It was higher for children with epilepsy (69%), visual impairment (62%) or physical impairment (57%) than children with intellectual impairment (50%) or hearing impairment (37%).

Table 3: Impact of disability on school attendance (children aged 5+)

		Child with disabilities	Neighbour control	Age and sex adjusted OR (95% CI)
Attends school	Yes	115 (62%)	159 (93%)	Baseline
	No	70 (38%)	12 (7%)	8.5 (4.3, 16.9)
Type of school	Pre-primary	93 (80%)	115 (72%)	Baseline
	Primary	23 (20%)	44 (28%)	0.5 (0.3,0.9)
School grade	1	32 (82%)	52 (72%)	Baseline
	2+	7 (18%)	20 (28%)	0.3 (0.1-1.0)

The qualitative study also showed that children with disabilities were excluded from schools.

The four key reasons parents gave for non-attendance at school were:

- 1. Lack of transport to school/ long distances**
- 2. Lack of support in schools**
- 3. Lack of funds for school fees**
- 4. Fear that their child might be teased or hurt by other children.**

Exclusion from school impacted on the family through reducing the opportunities for employment

"Since the child cannot walk well to school I am forced to carry him to school, sometimes we don't have time to take carry him to school and he has to stay at home, especially when I have to fetch firewood early in the morning."

"There is a school here [a special school in Lodwar] but you have to be able to pay"

"It is difficult if you have to sit here the whole day and care for him. When all the children have gone to school he is left alone. The mother might be in town and I might be collecting firewood or on the farm. He is then left on his own under the tree until someone comes home."

Childhood disability and receipt of aid

Receipt of aid in the last 3 months was relatively rare, as only 10% of families of children with disabilities received aid, compared to 7% of the controls, which may predispose the children towards malnutrition. Receipt of care did not differ between case and control households (Odds ratio=0.7, 95% confidence interval 0.4-1.3).

Children with disabilities were often not attending school, and therefore were less likely to be in School Feeding Programmes.



Young boy with a physical impairment

The lack of access of children with disabilities to School Feeding Programmes was cited in the qualitative study.

Families also reported that the disability of the child was a barrier to the access of other Feeding Programmes, because of difficulties in accessing the scheme.

Many key informants said that children with disabilities were generally hidden away at home most likely because of the stigma attached to disability as well as lack of awareness of services. Consequently, they were not seen in the health or nutrition programmes.

"When food is distributed at school it only reaches children with disabilities in school. It leaves out children not enrolled in school especially those under five years"
(KI)

"There is a food for work programme within the area but I'm not a beneficiary. There is no way I can leave the baby and go to work."

"B has not been part of any food programme, but we haven't exposed him to any of these programmes [why?] I was ashamed to take him out for a project."

Childhood disability and health

There were no differences between children with disabilities and neighbour controls in vaccination coverage, health status or care-seeking behaviour. Nor were there differences in receipt of vitamin A supplementation or deworming.

Childhood disability and feeding practice

Children with disabilities were more likely to have their food prepared differently, and twice as likely to report difficulties in feeding (Table 4).

There was no difference in the types of food eaten between children with disabilities and controls or the number of times the child was fed per day. We did not assess the quantity or quality of the foods eaten. There was no difference in breastfeeding practices between children with disabilities and those without.

Table 4: Relationship between disability and with feeding difficulties

		Child with disabilities	Neighbour control	Age and sex adjusted OR (95% CI)
Food differently prepared	Yes	29 (10%)	14 (5%)	2.1 (1.1-4.2)
	No	272 (90%)	269 (95%)	Baseline
Does child feed him/herself	Ever	55 (18%)	13 (4%)	6.5 (3.3,12.7)
	Never	249 (82%)	284 (96%)	Baseline
Difficulty feeding	No	252 (81%)	268 (89%)	Baseline
	Yes	59 (19%)	32 (11%)	1.9 (1.2-3.1)

These findings on frequent difficulties with feeding among children with disabilities were supported by the qualitative study for some of the children, for example, for children with cerebral palsy. Participants had the following to say:

"....it takes a long time for him to chew anything and swallow anything and so it takes a very long time to feed him and this can be a problem when we have to work." (child with cerebral palsy)

"The child is not able to feed himself. He is usually fed, but feeds without any difficulty. He feeds less than that of other children since he is fed. Usually a child who feeds herself is more likely to eat more compared to the one who is fed."

Childhood disability and anthropometry

Children with disabilities were on average shorter, with smaller arm span and length, and shorter tibia length in comparison to neighbour controls (Table 5). There were fewer differences in anthropometric characteristics when comparing children with disabilities to their sibling. Children with disabilities had significantly lower weight and smaller MUAC in comparison to either their sibling or neighbour control.

Table 5: Anthropometric measures and disability

	Child with disabilities Mean (SD*)	Family control Mean (SD*)	p-value**	Neighbour control Mean (SD*)	p-value**
Height	104.6 (18.8)	103.4 (17.2)	0.20	106.4 (16.0)	<0.001
Arm span	104.0 (19.2)	103.7 (17.9)	0.03	106.7 (16.7)	<0.001
Arm length	37.3 (7.2)	36.8 (7.2)	0.16	38.3 (6.5)	<0.001
Tibia	26.9 (6.1)	26.5 (5.7)	0.17	27.9 (5.2)	<0.001
Weight	14.9 (5.4)	15.1 (4.7)	0.006	16.0 (4.6)	<0.001
MUAC	14.6 (1.6)	14.9 (1.2)	0.002	15.0 (1.1)	<0.001

* Standard deviation. **Adjusted for age and sex

Children with disabilities had significantly lower weight for age, height for age, and BMI for age in comparison to either neighbour or sibling controls (Table 6). Differences in weight for height were found only between children with disabilities and neighbour controls.

Table 6: Malnutrition and disability

	Child with disabilities Mean Z score (SD*)	Family control Mean Z score (SD*)	p-value**	Neighbour control Mean Z score (SD*)	p-value**
Weight for age	-2.1 (1.6)	-1.5 (1.3)	<0.0001	-1.2 (1.4)	<0.0001
Height for age (Stunting)	-1.4 (1.8)	-0.9 (1.7)	0.02	-0.6 (1.8)	<0.0001
BMI for age	-1.6 (1.3)	-1.3 (1.1)	0.02	-1.3 (1.1)	0.001
Weight for height (Wasting)	-1.5 (1.4)	-1.2 (1.1)	0.08	-1.2 (1.2)	0.02

* Standard deviation. **Adjusted for age and sex

The prevalence of malnutrition was high in both controls without disabilities and children with disabilities (Table 7). Children with disabilities were 1.5-2.7 times more likely to be underweight for age, stunted and have low BMI for age in comparison to neighbour controls or family controls. Children with disabilities were almost twice as likely to be wasted in comparison to neighbour controls, but this difference was not apparent compared with siblings. These associations were not explained fully by adjustment for the presence of feeding difficulties.

Table7: Relationship between malnutrition and disability status

		Child with disabilities N (%)	Family control N (%)	Age- sex adjusted OR (95% CI)	Neighbour control N (%)	Age- sex adjusted OR (95% CI)
Underweight for age	Yes	158 (54%)	63 (34%)	2.2 (1.5-3.2)	86 (30%)	2.7 (1.9-3.7)
	No	136 (46%)	120 (66%)	Baseline	201 (70%)	Baseline
Stunting	Yes	74 (33%)	42 (23%)	1.7 (1.1-2.6)	57 (20%)	1.9 (1.3-2.9)
	No	151 (67%)	137 (77%)	Baseline	225 (80%)	Baseline
Low BMI for age	Yes	84 (37%)	47 (26%)	1.6 (1.1-2.5)	69 (24%)	1.8 (1.2-2.7)
	No	143 (63%)	132 (74%)	Baseline	219 (76%)	Baseline
Wasting*	Yes	40 (33%)	27 (24%)	1.5 (0.8-2.7)	31 (20%)	1.9 (1.1-3.4)
	No	80 (67%)	85 (76%)	Baseline	122 (80%)	Baseline

*Restricted to children <5 years only

DISCUSSION

Summary of results

This was a large study among children with disabilities using quantitative and qualitative methods, conducted in an area prone to food insecurity. The key findings are as follows:

1. Prevalence and type of disabilities:

- **The prevalence of moderate/severe disability was 0.7%.**
- **The majority of children with disabilities were boys**
- **Physical impairment was the most common type.**
- **There was poor uptake of health and rehabilitation services.**

These figures are in line with the estimates from the Key Informant Method Study of Childhood Disability in Bangladesh and Pakistan, which estimated the prevalence of moderate/severe impairment of 0.9% in Bangladesh and 0.5% in Pakistan. [14] Physical impairment was the most common type of impairment in both settings. The higher prevalence of disability in boys as compared to girls was also reported in the UNICEF survey.[7]

2. Feeding, malnutrition and disability:

- **Malnutrition was common in both children with disabilities and controls without disabilities**
- **Children with disabilities more likely to be malnourished**
- **Children with disabilities less likely to be at school and in school feeding programmes**

The central finding of the study is that children with disabilities are more likely to be malnourished compared to those without. This is likely to be because:

- Children with disabilities were less likely to attend school, and so were not included in the School Feeding Programme
- Children with disabilities were more likely to report feeding difficulties
- Disability as a consequence of malnutrition (e.g. rickets) was relatively common
- Families with children with disabilities may have more difficulties accessing aid or undertaking productive work
- Children with disabilities may face neglect, or reduced access to care

Other studies have also investigated the link between malnutrition and childhood disability. The UNICEF multiple Indicator Cluster Survey including nearly 200,000 children across 15 countries showed that disability was significantly related to stunting in 5 of the countries, and to being underweight in 7 of the countries. [5] Others have reported more mixed results, but agree that malnutrition is most common in children with neurological or physical impairments, [4, 6, 7, 9, 15-17] and that this may be linked to feeding difficulties. [4]

3. Education, poverty, health, aid receipt and disability:

- **Children with disabilities were often not included in education.**
- **No clear relationship between poverty and childhood disability**
- **Families of children with disabilities experience difficulties accessing aid.**

With respect to previously published studies:

- Data is lacking to address inclusion of children with disabilities in aid receipt.
- A large review found that the relationship between childhood disability and socio-economic circumstances was “inconsistent and inconclusive” across 24 primary studies from low and middle income countries, [18] supporting the lack of relationship shown in this study.
- The exclusion of children from education has been demonstrated and is well established. [1]

Strengths of the study

- This study used mixed methods, collecting qualitative and quantitative data.
- The quantitative study was large, including children with disabilities as well as two sets of controls.
- The presence of disability was assessed both through a questionnaire as well as examination by a paediatrician.
- Detailed anthropometric measures were taken, as well as a comprehensive questionnaire.

Limitations of the study

- The key informant method is unlikely to identify all children with disabilities in the community, and so may underestimate the prevalence.
- There were missing data in a number of categories.
- It was not possible to measure anthropometry on all children.
- Sophisticated measures of anthropometry, such as DXA scans, could not be used.

Implications

A central implication of our findings is the need to address malnutrition in Turkana, particularly among children with disabilities. There is also the need for further focus on including children with disabilities in education.

Lack of inclusion of children from education and other programmes are contrary to the spirit of two key conventions relevant to children with disabilities: the UN Convention on the Rights of the Child, [19] and the UN Convention on the Rights of Persons with Disabilities. [2]

A range of activities could be promoted to tackle these issues, such as targeted feeding programmes or support for families on feeding practices, but the evidence base on what works needs to be strengthened substantially in order to identify scalable interventions. [20, 21]

Recommendations:

1. **Children with disabilities should be targeted in food aid and food assistance programmes:** Direct inclusion of children with disabilities in food aid and food assistance interventions as a key vulnerable group
2. **Children with disabilities should be included in mainstream food assistance programmes:** Take steps to ensure that children with disabilities can access existing nutrition and food assistance programmes.
3. **Efforts are needed to include children with disabilities in education.** Explore models of 'good practice' from within Kenya and the region.
4. **Advocacy and communication is needed** to increase knowledge (at all levels) which will promote mainstreaming of disability into various sectoral programmes as well as encourage social change at all levels including community members.
5. **Partnerships need to be strengthened:** Enhance partnerships with key stakeholders such as Pediatrics and surgical association of Kenya as well as UNICEF who can be a key avenue to advocate for disability to county government to increase availability of treatment and rehabilitative services at the for children with disabilities.
6. **Establish simple and clear referral pathways** for treatment and rehabilitation services for children with disabilities.
7. **Research is needed:** More research is needed to better understand the lives of children with disabilities. The mixed methods approach worked well and can be extended to other studies.

Conclusions

- **Children with disabilities are particularly vulnerable to malnutrition, within an area of food insecurity.**
- **Efforts need to be made to include these children within food supplementation programmes, and school based programmes alone may be inadequate to meet this need.**
- **Exclusion of children with disabilities from education is also a priority area to be addressed.**

REFERENCES

1. WHO, *World Report on Disability*. 2011, Geneva: World Health Organisation.
2. United Nations, *Convention on the rights of persons with disabilities*. 2006, United Nations: New York.
3. Black, R.E., et al., *Maternal and child undernutrition and overweight in low-income and middle-income countries*. *Lancet*, 2013. **382**(9890): p. 427-51.
4. Yousafzai, A.K., S. Filteau, and S. Wirz, *Feeding difficulties in disabled children leads to malnutrition: experience in an Indian slum*. *The British journal of nutrition*, 2003. **90**(6): p. 1097-106.
5. Gottlieb, C.A., et al., *Child disability screening, nutrition, and early learning in 18 countries with low and middle incomes: data from the third round of UNICEF's Multiple Indicator Cluster Survey (2005-06)*. *Lancet*, 2009. **374**(9704): p. 1831-9.
6. Tompsett, J., A.K. Yousafzai, and S.M. Filteau, *The nutritional status of disabled children in Nigeria: a cross-sectional survey*. *Eur J Clin Nutr*, 1999. **53**(12): p. 915-9.
7. Wu, L., et al., *Association between nutritional status and positive childhood disability screening using the ten questions plus tool in Sarlahi, Nepal*. *Journal of health, population, and nutrition*, 2010. **28**(6): p. 585-94.
8. Yousafzai, A.K., et al., *Beliefs about feeding practices and nutrition for children with disabilities among families in Dharavi, Mumbai*. *Int J Rehabil Res*, 2003. **26**(1): p. 33-41.
9. Kerac, M., et al., *The interaction of malnutrition and neurologic disability in Africa*. *Semin Pediatr Neurol*, 2014. **21**(1): p. 42-9.
10. Kett, M. and M. van Ommeren, *Disability, conflict, and emergencies*. *The Lancet*, 2009. **374**(9704): p. 1801-1803.
11. OCHA (United Nations Office for the Coordination of Humanitarian Affairs), *Turkana Nutrition and Mortality Survey*. July 2012.
12. WHO, *WHO Child Growth Standards*. 2006, World Health Organisation: Geneva.
13. Kenyan National Bureau of Statistics, *Kenya Population and Housing Census*. 2009, Kenya National Bureau of Statistics: Nairobi.
14. Murthy, G. and I. Mactaggart, *The Key Informant Child Disability Project in Bangladesh and Pakistan*. 2013, ICED: London.
15. Colver, A., C. Fairhurst, and P.O. Pharoah, *Cerebral palsy*. *Lancet*, 2014. **383**(9924): p. 1240-9.
16. Socrates, C., et al., *Poor nutrition is a serious problem in children with cerebral palsy in Palawan, the Philippines*. *Int J Rehabil Res*, 2000. **23**(3): p. 177-84.
17. Gladstone, M., et al., *Assessment of neurodisability and malnutrition in children in Africa*. *Semin Pediatr Neurol*, 2014. **21**(1): p. 50-7.
18. Simkiss, D.E., et al., *Childhood disability and socio-economic circumstances in low and middle income countries: systematic review*. *BMC pediatrics*, 2011. **11**: p. 119.
19. United Nations, *Convention on the Rights of the Child*. 1989, United Nations: New York.
20. Tomlinson, M., et al., *Research priorities for health of people with disabilities: an expert opinion exercise*. *Lancet*, 2009. **374**(9704): p. 1857-62.
21. Yousafzai, A.K., P. Lynch, and M. Gladstone, *Moving beyond prevalence studies: screening and interventions for children with disabilities in low-income and middle-income countries*. *Arch Dis Child*, 2014. **0**: p. 1-9.

This study was funded by CBM and was conducted in partnership between: Kenyan Red Cross Society; CBM East Africa Regional Office; International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine

Thank you to all the Kenya Red Cross Volunteers (KCRS) who supported the field work in a multitude of ways. Thank you to Dr Dr Hillary Rono, Zonal Ophthalmologist Western Kenya, Ministry of Health.

And finally a huge thanks to the families who gave up their time to be interviewed and share their personal stories.

KRC: James Kisia, Victoria Mwenda, Velma Nyapera, David Otieno and Hellen Mwangovya

CBM: David Munyendo and Kirstin Bostelmann

LSHTM: Maria Zuurmond, Severine Frison, Hannah Kuper and Jenny Evans