International Centre for Evidence in Disability

LONDON SCHOOL of HYGIENE & TROPICAL MEDICINE

The Malawi Key Informant Child Disability Project

International Centre for Evidence in Disability

University of Malawi

COSECSA Oxford Orthopaedic Link

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EXECUTIVE SUMMARY

Background

Data on the prevalence and causes of childhood disability are lacking in Malawi and generally in Low and Middle Income Countries (LMIC). These data are needed for informing policies, services and evidence-based advocacy for children with disabilities in LMIC. The Key Informant Method (KIM) is a novel method for generating these data. KIM focuses on training community volunteers to identify local children who may have disabilities, who are then screened by medical professionals and referred on for appropriate health and rehabilitation interventions. Consequently, the method offers an alternative to population-based surveys of disability in children, which can be costly and time consuming.

Aims and objectives

The aim of this study was to use the KIM to estimate the prevalence of moderate/severe physical, sensory and intellectual impairments and epilepsy among children in two districts (Ntcheu and Thyolo) in Malawi. Epilepsy was included as a health condition which is often disabling.

Objectives:

- To estimate the prevalence and cause of moderate/severe physical, vision, hearing and intellectual impairment and epilepsy among children under 18 years in Ntcheu and Thyolo districts, Malawi.
- To estimate the needs for rehabilitation and referral services for children with disabilities in Malawi.
- To develop a network of providers of clinical services and rehabilitation for children identified with the different impairments.
- To develop a database of children with these impairments in the study areas who could be included in future research.

Methods

This study focussed on the following types of disability:

- moderate/severe bilateral sensory (hearing or vision) impairment.
- moderate/severe physical impairment.
- intellectual impairment.
- epilepsy (a health condition which is often disabling).

Five hundred Key Informants (KIs) from the community were trained in the identification of the different impairments/epilepsy included in this study, case finding methods and disability sensitisation. Identified children were listed on a registry and invited to attend a screening camp where they underwent assessment by medical professionals. The carers of a sample of 240 children who did not attend the camps were interviewed to explore reasons for non-attendance.

Key findings

- Approximately 15,000 children were listed by KIs as potentially having a disability of whom 7,220 (48%) attended a screening camp.
- Of the children screened 39% (n=2,788) were identified as having at least one of the impairment types/epilepsy included in the study.
- The estimated prevalence of impairments/epilepsy was 17.3/1,000 children.
- Physical impairment (39% of all children with disabilities identified) was commonest impairment type followed by bilateral hearing impairment (27%), intellectual impairment (26%), epilepsy (22%) and bilateral vision impairment (4%). Fourteen percent of the children had multiple impairments.
- Nearly three-quarters of children with impairments/epilepsy of school-age were attending school. However, attendance varied by impairment type and was lowest among children with multiple impairments (38%).

Conclusions

1. The KIM successfully identified more than 2,500 children with different types of disability in two districts in Malawi.
2. The KIM helped to identify service needs for children with disabilities including the following:
    - It is estimated that there are 3,520 children per million population with physical impairments in this setting of whom 2,100 could benefit from physiotherapy or occupational therapy and 300 of whom are in need of a wheelchair.
    - There are an estimated 1,800 children per million population with hearing impairment from avoidable causes that could be prevented or treated though provision of basic primary level ear and hearing care.
    - There is a significant treatment gap for epilepsy: only 50% of children with epilepsy were reported to be receiving treatment.

   - Corneal opacity was the leading cause of vision loss, highlighting a need to strengthen and sustain measles immunization / vitamin A supplementation programmes.
   - There are an estimated 2,100 children per million with intellectual impairment, but relevant services in this setting are considered lacking.
3. As well as providing data on child disability that can be used for advocacy and to inform planning, this method study also has an important capacity building and disability awareness raising component with training of 500 KIs from the community in disability awareness and mapping of medical and rehabilitation services.
4. Attendance at the camps was relatively low and this needs to be addressed in future applications of the KIM.
5. Children with impairments/epilepsy screened at the camps were referred to medical and rehabilitation services. Further work is needed to determine the uptake and experiences of these services.
6. The majority (73%) of children with disabilities were attending school. However, information is needed on the educational experiences of children with disabilities and the extent to which they are included in comparison to their non-disabled peers.

Recommendations

1. To use the results from the study to plan and advocate for services for children with disabilities, in particular for:
   - Physiotherapy and occupational therapy for children with physical impairments.
   - Development of basic primary level ear and hearing care.
   - Provision of medication for children with epilepsy.
   - Strengthening measles immunization / vitamin A supplementation programmes.
   - Developing services for children with intellectual impairment.
2. To consider modifying the KIM to enable screening of children in their households to reduce loss to follow up.
3. To increase attention on improving school attendance and assess the quality of education among children with disabilities.

INTRODUCTION

There are estimated to be more than one billion people living with disabilities in the world.[1] However, reliable data on the prevalence, types and causes of disability in children is lacking, particularly in low and middle income settings (LMIC). The World Report on Disability estimates that there are approximately 93 million children aged 0-14 years living with “moderate or severe disability” equating to one in twenty children globally (5.1%).[1] Country level prevalence estimates are limited and vary widely from <1% to >40% of the child population.[2] This variation is due, in part, to the different survey and disability assessment methods used.

The World Report on Disability highlighted the need for ‘comparable and complete data collection [on disability] especially in developing countries’.[1] Such data are important for informing appropriate planning of policies and services and evidence-based advocacy for children with disabilities in LMIC. Furthermore, evidence suggests that children with disabilities are more likely to come from poorer households, are less likely to attend school, experience greater vulnerability to violence and more likely to suffer from malnutrition compared to non-disabled children.[1, 3, 4] However, there is very little reliable data on child disability, hampering advocacy and effective programme planning.

The Key Informant Methodology

Different approaches can be used to identify children with disabilities at the population level - either for inclusion in interventions or to estimate numbers and facilitate planning of policies and programmes.[5] Door-to-door surveys can be used, but these can be very time consuming and expensive. The Key Informant Method (KIM) is an alternative approach.[6]

The KIM involves training community level volunteers, called Key Informants (KIs), to identify and list children who potentially have impairments or health conditions using specific criteria. The children identified by the KIs are assessed by health professionals at a screening camp using objective clinical criteria, to verify whether they have a moderate or significant impairment. All children identified with unmet health care needs are referred to appropriate services that are identified at the start of the project. In addition to generating much needed disability statistics, the reliance in KIM on community involvement and establishing links with key stakeholders and service providers encourages capacity building and knowledge sharing about disability.[5]
In 2008-12 the KIM was developed to identify children with vision, hearing, physical impairment or epilepsy in Bangladesh and Pakistan. The approach worked well; KIs effectively identified most of the children with these impairments/epilepsy in the community and it generated important data on childhood disability.[7] It also lead to further research, including on the barriers

to uptake of referral[8] and the development of a training manual for parents of children with cerebral palsy.[9] To date, KIM has not been used to estimate the prevalence and types of different impairments (other than vision) in Africa and a large data gap remains on childhood disability in the region.

Child disability in Malawi

Malawi is a small country in Southern Africa and has an estimated population of about 16 million (http://data.worldbank.org/country/Malawi) of whom more than half are children. It is one of the poorest countries in the world, ranked 170 out of 186 countries in the UN human development index.[10] Data on the prevalence, types and causes of disability among children in Malawi are lacking, as highlighted by UNICEF in their recent report on 'Promoting the rights of children with disabilities in Malawi'.[11] The 2008 Malawi Housing and Population Census estimated the overall prevalence of disability to be 2.4% among children and 3.8% in the general population.[12] Hearing loss was the commonest type of disability in all ages (23%), followed by visual impairment (17%), mobility problems (16%) and communication difficulties (9%). However, this survey lacked verification of self-reported limitations by clinical examination and did not use tools specific for children. Studies of epilepsy in Malawi have generated varied estimates from 5.1 per 1,000[13] to 28 per 1,000[14] for all ages. Up-to-date information on prevalence, causes and types of childhood disability in Malawi are urgently needed in order to inform planning of appropriate services for children with disabilities.

Malawi ratified the UN Convention on the Rights of the Child in1991 and the UN Convention on the Rights of Persons with Disabilities (CRPD)[15] in 2009. In 2012 the Disability Act was introduced which is rooted in the social model, promoting the rights of people with disability in line with the CRPD. However, research by UNICEF and the Centre for Social Research in Malawi suggests that this legislation is not being fully implemented.[16] The research also found that disability is not given high priority at government level and that funds allocated to the disability sector remain inadequate. Further, awareness amongst national level stakeholders (including civil servants) of the major legislations and conventions for children with disabilities was found to be low. This is despite evidence in this setting that children with disabilities face significant challenges in access to healthcare, education, sanitation facilities, skills development and employment opportunities as well as social challenges in forming relationships.[11]

Definitions

What is disability? The World Health Organisation International Classification of Functioning, Disability and Health (ICF) is a biopsychosocial model of disability that incorporates health conditions and functional impairments, activity limitations and participation as well as the environment. Using this framework, the United Nations Convention on the Rights of Persons with Disabilities[15] defines disability as “long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder [a person’s] full and effective participation in society on an equal basis with others”.

This KIM study focussed on the impairment component of disability, which is defined by the ICF as ‘a loss or abnormality in body structure or physiological function’. Specifically this study measured hearing, vision, physical and intellectual impairments as well as epilepsy (an often disabling health condition). In LMIC, where access to medical treatment, rehabilitation and access to education and other services are limited, people with impairments are often disabled[17], but, we did not specifically measure activities, participation or environmental components of disability in this study.

Child: We define the child according to the United Nations Convention on the Rights of the Child as a person under 18 years of age.

AIM OF THE STUDY

The aim of this study was to use the KIM to estimate the prevalence of moderate/severe physical, sensory and intellectual impairments and epilepsy among children in two districts (Ntcheu and Thyolo) in Malawi. Epilepsy was included as a health condition which is often disabling.

Objectives:

- To estimate the prevalence and cause of moderate/severe physical, vision, hearing and intellectual impairment and epilepsy among children under 18 years in Ntcheu and Thyolo districts, Malawi.
- To estimate the needs for rehabilitation and referral services for children with disabilities in Malawi.
- To develop a network of providers of clinical services and rehabilitation for children identified with the different impairments.
- To develop a database of children with these impairments in the study areas who could be included in future research.

METHODS

Study setting

The study was undertaken in two districts in Malawi: Thyolo (Southern region) and Ntcheu (Central region). In each district four out of the eight Traditional Authorities were included in the study. This gives a total estimated study population of 338,235 children (< 18 years) according to the 2008 census data, updated to reflect population growth.

Project preparation

i. Stakeholder meetings

A series of meetings were held between the research team, the UK project coordinator and local stakeholders, including the District Health Officers and District Environmental Health Officers. The purpose of these meetings was to present the study purpose and methodology, and to obtain stakeholder input on the study location, suitable KI training sites and screening camp locations, as well as identification of the KIs and their coordinators.

ii. Referral services mapping

Comprehensive mapping of referral services was undertaken before the start of the survey (e.g. CBR programmes, ophthalmic units, orthopaedic units). This included meeting with relevant stakeholders and service providers to develop a list and establish links with available services in the study areas for each of the specific impairments included in the study.

iii. Key Informant training

Area Coordinators were engaged (via the District Environmental Health Officers) to mobilise and supervise the KIs. KIs were identified by the Area Coordinators from existing pools of volunteers who regularly assist with public health campaigns, community mobilisation and dissemination of important health-messages for example on vaccinations, guinea worms, etc. A total of 500 KIs were trained (250 per district) plus 12 Area Coordinators. The volunteers were trained in groups of approximately 25 KIs per session over 10 training workshops in each district. The trainings followed a standardised format and included:

- Disability sensitisation
- Identification of the different impairments
- Methods for case finding
- Procedures for the screening camps

Materials used in the training included specially designed flipcharts and hand-out information sheets produced in the local language which contained a) information and illustrations regarding the specific impairments to be identified and b) instructions on how to conduct case finding and complete the registry.

Identification of children with disabilities

After their training, the KI volunteers were given 3-6 weeks to identify children with the specific impairments/epilepsy included in the study. All children identified were listed on a standardised registry form and invited together with a guardian to one of the screening camps. A few weeks prior to the camp meetings were held at or close to each anticipated camp location with the relevant KIs and Area Coordinator. The aim of this meeting was to i) review the registers of listed children ii) ensure that children experiencing conditions outside of the remit of the project were not being invited and iii) confirm the locations and dates of the camps. The meetings also informed planning of the subsequent camps; if more than 500 children were listed by KIs then ‘overflow’ camps were held so that children could be seen over two camps rather than one.

KIM screening camps

i. Screening teams

The team conducting the camps was comprised of medical and non-medical personnel. The team underwent training in the study methodology and protocols (led by MT) and standardised clinical diagnosis (led by relevant medical specialists). The different team members and their roles are shown in table 1 below:

Table 1 Screening camp team roles

Team member	Role
Key Informant volunteer	Checking children against the register and obtaining consent
Social/rehabilitation worker	Registration and collection of demographic and education data
Rehabilitation technician	Impairment screening questions, clinical history
Nurse 1	Epilepsy assessment
Nurse 2	Intellectual impairment assessment
Orthopaedic clinical officer	Physical impairment assessment
Ophthalmic clinical officer	Vision impairment assessment
ENT clinical officer	Ear examination
Audiologist	Hearing assessment

ii. Data collection

A set of screening questions were used to identify children at risk of the different impairments/epilepsy. Based on the responses to these questions, children were directed to the relevant clinical station as follows:

Screening question:		**Clinical station referred to if 'yes'**
Does your child have problems seeing?	→	Vision
Does your child have problems hearing?	→	Hearing
Does your child have fits/convulsions?	→	Epilepsy
Does your child have a problem with their body that makes it hard for them to do daily activities like feeding or washing?	→	Orthopaedics
Does your child have problems walking?	→	Orthopaedics
Does your child have problems talking?	→	Hearing and intellectual
Does your child have problems with learning/understanding?	→	Intellectual

Standardised data collection forms were used at the screening camps (see Appendix 1) which included: socio-demographic details (age, family income, education), rehabilitation, clinical history, clinical examination and referral recommendations. Assessment for each impairment and epilepsy was conducted by a relevant medical professional using standardised methods and definitions. The methods and case definitions used are shown in table 2 below.

Table 2 Clinical assessment method and definitions of impairment

Impairment/health condition	**Assessment method**	**Case definition**
Epilepsy	Set of 8 screening questions (see Appendix 1).	Clinician confirmed epilepsy based on responses to screening questions.
Intellectual impairment	Set of 12 screening questions developed in consultation with local occupational therapist (see Appendix 1).	Clinician confirmed. Responds ‘no’ to at least 3 of the age-relevant screening questions and/or has Down’s Syndrome, microcephaly or hydrocephaly.
Moderate/severe physical impairment	Standardised observation of activities (ability to hold and change position, mobility and hand function) and physical examination.	Clinician confirmed moderate/severe physical impairment lasting more than one month (or from birth) affecting functioning based on observation of activities and physical examination.
Moderate/severe vision impairment	0-2 years: fix and follow 3-4 years: counting fingers (child asked to count/copy number of fingers shown by ophthalmic clinical officer at 6 meters, both eyes together) ≥5 years: visual acuity assessment using tumbling ‘E’ chart Eye examination using direct ophthalmoscope and retinoscope.	0-2 years: unable to fix and follow. 3-4 years: unable to count fingers at 6 meters (approximately equivalent to VA<6/60). ≥5 years: presenting VA <6/60 in better eye.
Moderate/severe hearing impairment	6 months-4 years: Otoacoustic Emissions (OAE) tests. ≥5 years: Pure Tone Audiometry (PTA). Ear examination using an otoscope.	6months-4 years: Fails OAE both ears. 5+ years: >35 dBHL in both ears.

iii. Referral Procedures

Following their medical examination, children and their guardians were provided with a diagnosis and relevant information regarding this diagnosis and were referred to onward services as appropriate. Referrals were made to health facilities as well as other services (e.g. Community Based Rehabilitation) where available.

Children and their guardians were seen by an exit team who checked the forms for completeness and confirmed and re-iterated information regarding referrals. The child's "health passport" was stamped with a date and the name of the project, and any referrals made were recorded in the passport. These passports are usually issued by health-facilities, but were provided at the camps for any child who did not have/bring one. If a child did not present with any of the targeted impairments but required follow up, they were referred to the nearest Health Post, Health Centre, or District Hospital depending on their presenting concern (usually an acute medical problem).

Quality assurance

The following steps were undertaken for quality assurance:

- Training of KIs and medical teams.
- Supervision of screening camp by the project manager (MT).
- Checking of forms by project manager and camp exit team.
- Pre-coded data entry forms to reduce data entry errors.
- Data entry databases with in-built consistency checks.
- Validation of data entry through double entry of 10% of forms.
- Data cleaning.

Understanding reasons for non-attendance at screening camps

Approximately half of the children listed by KIs as having an impairment/epilepsy did not attend a screening camp. To explore the reasons for this relatively low attendance, in-depth interviews were first conducted with carers of 20 non-attending children, KIs and area coordinators from across different Traditional Authorities. In addition parents/carers of 295 children were randomly selected for interview using structured questionnaires by trained interviewers. Interviews were conducted at a central location in their village or at participant's homes if they were unable to attend the central place. The structured questionnaires included:

1. Age and gender
2. Reported functioning: assessed using the Washington Group six-question set on functioning.[16, 18]
3. Awareness and knowledge about screening camps*
4. Reported reasons for non-attendance

*The questions on awareness, knowledge and reasons for non-attendance were developed using findings from the in-depth interviews.

Data entry and analysis

All data were entered into an Access database. Ten percent of the forms were double entered and compared to verify the quality of the data entry. Data cleaning and analyses were undertaken using STATA.

In order to estimate the total prevalence across the study areas, we have made the following assumptions: a) the total proportion of children with any impairment/epilepsy and b) the distribution of impairments/epilepsy were the same among children who did and did not attend the camps. We also undertook sensitivity analysis varying the assumed proportion of non-attending children to ±10% of the proportion observed among the attenders. The denominator used to calculate the prevalence of impairments is the total number of children living in these study areas (338,235). This data is taken from the 2008 census, updated to reflect the estimated population growth. Appendix 2 details how these estimates were derived.

Ethical approval

Ethical approval was obtained from the College of Medicine Research Ethics Committee, Malawi and the London School of Hygiene and Tropical Medicine. The study purpose and procedures were explained to the child and the accompanying parent/carer and signed/thumb-printed consent was obtained from the parents/carers of all participating children. All information collected from participants was kept confidential to the research team and participants were assigned a unique identifier number used in the analysis and reporting to ensure anonymity. All children requiring services were referred as appropriate.

RESULTS

Study population

Approximately 15,000 children were listed by KIs as potentially having a disability (table 3). This number is an estimate as not all 500 KIs registers were available at the end of the project due to logistical difficulties. Based on data from 380 registers, each KI listed an average of 30 children. Therefore we assumed a total of 15,000 listed children for 500 KIs.

Of the 15,000 listed children, 7,220 (48%) attended one of 33 screening camps in Thyolo and Ntcheu districts. Of the 7,220 children screened, 2,788 (39%) were identified as having at least one of the following: moderate/severe vision or hearing impairment, physical impairment, intellectual impairment or epilepsy. The remaining children did not meet the study criteria.

Table 3 Children attending the screening camps and screening positive for impairment or epilepsy

Group	Number	%
Children listed by KIs with suspected impairment*	15,000	
Children listed by KIs attending assessment camps	7,220	48%
Children with an impairment/epilepsy condition as per study definition	2,810	39%

*NB: This number is estimated as not all 500 KIs registers were available at the end of the project. Based on data from 380 registers, each KI listed an average of 30 children. Therefore we assumed a total of 15,000 listed children for 500 KIs.

Demographic and socio-economic characteristics

Among the cohort of 2,810 children with an impairment/epilepsy, 48% were female (Table 4) and approximately half came from each district (53% from Thyolo, 46% from Ntcheu). The vast majority (93%) of children were from families in the lowest monthly income group (<$30). Forty percent of all primary caregivers were illiterate and just under half (46%) had attended primary school. Only 7% of primary caregivers had attended secondary school.

The majority of children identified to have an impairment/epilepsy that were of school-going age (age 5+) were attending school (73%). School attendance was highest among the younger children rather than the older children (5-9 years: 77%, 10-14 years: 80%, 15-18 years: 57%). Among children attending school 7% were at nursery school, 92% were at primary and 2% were at secondary school. Most of these children (82%) were in the correct school level for their age (e.g. 6-13 years for primary school and 14-17 years for secondary) although 15% of children aged more than 14 years were still attending primary school. The vast majority of school-going children were at public schools (96%) and nearly all (99%) were in mainstream education rather than ‘special’ schools.

The reported reasons for non-attendance at school are shown in Figure 1. Having an ‘illness’ lasting more than one month was the most common reason given (44%) for not attending. Environmental (school not accessible) and attitudinal barriers (refused by school/negative attitudes of students) related to disability were reported by 17% of children.

Table 4 Socio-demographic characteristics of children with impairments/epilepsy

	N	%
Age (years)		
0-4	619	23%
5-9	903	34%
10-14	760	28%
15-18	456	17%
Sex*		
Males	1,117	52%
Females	1,014	48%
District		
Thyolo	1,286	46%
Ntcheu	1,498	53%
Monthly Family Income (Malawian Kwacha)		
<12,000	2,488	93%
12,000-50,000	181	7%
>50,000	12	0.5%
Literacy/education of parent		
Illiterate	1,039	40%
Can read/write	182	7%
Primary education	1,219	46%
Secondary education	185	7%
Currently attending school**		
No	449	27%
Yes	1,239	73%

*Missing data; **Restricted to children of school going age (6-18 years)

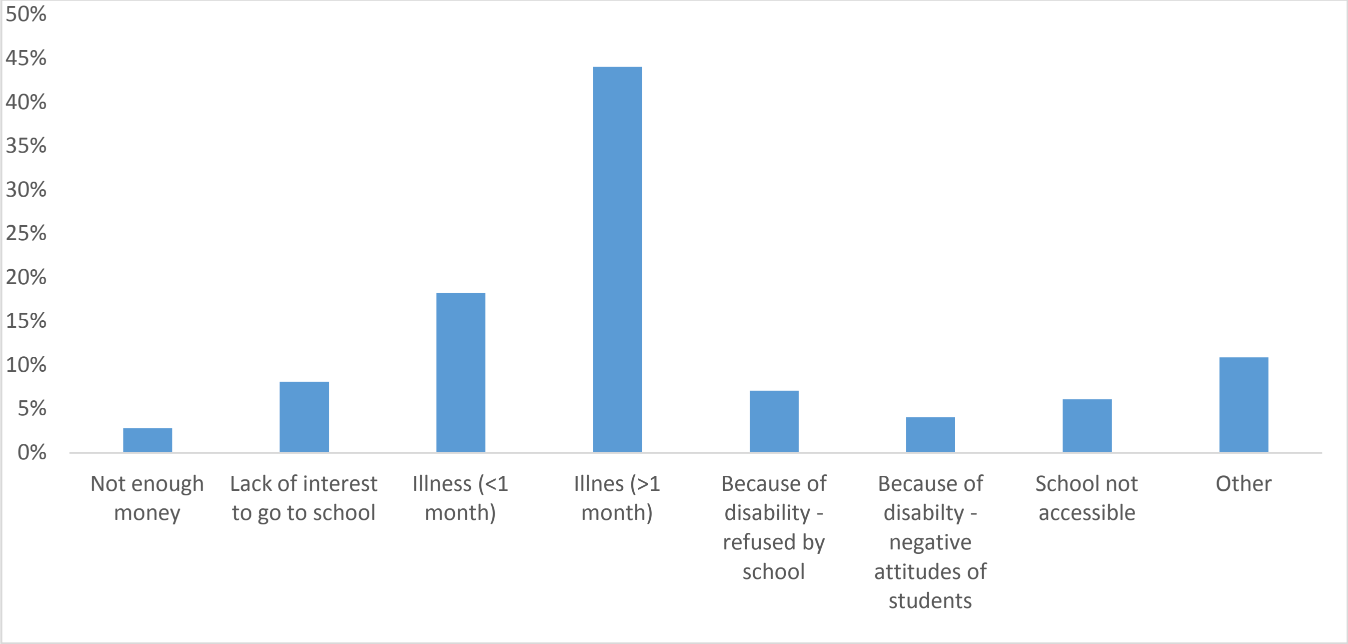


Figure 1 Reported reasons for not attending school among children of school-going age.

Prevalence of impairments and epilepsy

A total of 2,810 children were confirmed to have one or more impairment/epilepsy. Physical impairment (39%) was the commonest group followed by bilateral hearing impairment (27%), intellectual impairment (26%), epilepsy (22%) and bilateral vision impairment (4%). Fourteen percent of the children had multiple impairments.

The estimated combined prevalence of any of the impairments/epilepsy included in the study was 17.3/1,000 children. Table 5 shows the and prevalence estimates for each of the different impairment/epilepsy groups. This estimate is based on the assumption that the prevalence of disability was the same among children who did and didn’t attend the examination camp. We undertook a sensitivity analysis assuming first that the prevalence was 10% lower among the non-examined children, and then that it was 10% higher, and estimated the impact on the overall prevalence.

Table 5 Adjusted prevalence estimates of impairments/epilepsy in children in study area

Impairment/health condition	Number*	Prevalence* per 1,000 (95% CI)	Prevalence Range**	No. Per million total population***
Physical impairment	2,247	6.6 (6.3-6.9)	5.8-7.6	3,520
Hearing impairment	1,550	4.6 (4.4-5.8)	4.0-5.3	2,453
Epilepsy	1,258	3.7 (3.5-3.9)	3.3-4.3	1,973
Intellectual impairment	1,452	4.3 (3.8-4.2)	3.7-4.8	2,133
Visual impairment	243	0.7 (0.6-0.8)	0.7-0.8	373
Multiple impairments	806	2.4 (2.2-2.6)	2.1-2.7	1,280
Any impairment/epilepsy	5,844	17.3 (16.9-17.7)	15.0-19.6	9,066

* The number and prevalence estimates are adjusted based on the assumption that the prevalence of disability was the same among children who did and didn't attend the examination camp **The prevalence range is based on sensitivity analysis assuming the proportion of non-attenders having an impairment/epilepsy was ±10% of the actual proportion among attenders. NB: Appendix 1 details how these prevalence estimates were calculated
*** Per million total population of all ages, not population of children

Causes of physical impairment

The causes of physical impairment are shown in table 6. There were a total of 1,265 diagnoses for the 1,094 children with physical impairments. A neurological diagnosis was the most common and was evident in 54% (n=591) of all children with physical impairment, followed by congenital (n=215, 20%), acquired non-traumatic (n=194, 18%) and acquired trauma (n=145, 13%) diagnoses. The most common health condition was cerebral palsy (accounting for a quarter of all children with physical impairment), followed by para/quadra/tetri/hemi-plegia (13%).

Table 6 Physical impairment diagnoses

DIAGNOSIS	N	**%***
1. Congenital		
Polydactyly	13	1%
Syndactyly	10	1%
Other upper limb deformity	26	2%
Club foot	52	4%
Other lower limb deformity	58	5%
Upper and Lower Limb deformity	9	1%
Spine deformity	21	2%
Cleft lip or cleft palate	9	1%
Other congenital deformity	21	2%
Cause not given	5	0.4%
TOTAL	**224**	**18%**
2. Trauma		
Burn contracture	45	4%
Fracture malunion	15	1%
Head injury	1	0.1%
Recurrent/chronic dislocation	5	0.4%
Post traumatic joint stiffness	28	2%
Tendon problem	2	0.2%
Muscle problem	2	0.2%
Peripheral nerve problem	15	1%
Amputation	16	1%
Cause not given	20	2%
TOTAL	**149**	**12%**
3. Neurological		
Epilepsy	56	4%
Developmental delay	59	5%
Cerebral Palsy	282	23%
Para/quadra/tetri/hemi-plegia	138	11%
Peripheral nerve palsy	25	2%
Other neurological	137	11%
Cause not given	2	0.2%
TOTAL	**698**	**55%**
4. Acquired non-traumatic		
Joint infection	5	0.4%
Bone infection	19	1.5%
Skin wound/infection	4	0.3%
TB spine/spine infection	1	0.1%
Degenerative joint infection	4	0.3%
Non infective non traumatic joint infection	1	0.1%
Bow legs	26	2%
Knock knees	38	3%
Other joint deformity	9	1%
Bone tumour	8	1%
Soft tissue tumour	13	1%
Skin tumour	5	0.4%
Spinal deformity – kyphosis	10	1%
Limb pain limiting function	8	1%
Other	39	3%
Cause not given	1	0.1%
TOTAL	**194**	**15%**

*Some children had multiple diagnoses. Percentages in this table are calculated out of the total number of diagnoses (n=1,265) rather than individual children.

The majority (60%) of the children with physical impairment had not received any treatment in the past, 17% had previously had physical therapy and 12% had received surgery. The medical/rehabilitation services recommended for children with physical impairment in this study are shown in table 7. Physical therapy was the most commonly recommended service (44%) followed by surgery (17%) and occupational therapy (14%).

Table 7 Services recommended for children with physical impairment

Treatment needed	Number	%	Extrapolated number of children needing treatment per million population
Physical therapy	514	47%	1,654
Surgery	204	19%	669
Occupational therapy	159	15%	528
Wheelchair	83	8%	282
Medication	72	7%	246
Appliance/orthosis	32	3%	106
Mobility aid	26	2%	70
Tricycle	20	2%	70
Plaster of Paris	19	2%	70
x-ray	14	1%	35
Prosthesis	10	1%	35
Special seating	8	1%	35
Other	8	1%	35
TOTAL	1,169		3,837

*Denominator is the total number of children with physical impairment

Aetiology of hearing Impairment

All children with bilateral moderate/severe hearing impairment, as determined by OAE and audiometry, underwent an ear examination by an ENT Clinical Officer. Just under half of the children with hearing impairment had a perforated ear drum and 36% had evidence of discharge in the middle ear (table 8). Wax was evident in one third of the children. Inflammation, foreign bodies, retraction and red/bulging ears were less common (<5%). The majority (73%) of children with bilateral hearing impairment had one or more of these symptoms (indicating conductive hearing loss) while 25% did not have any (indicating sensori-neural causes of hearing loss). Extrapolating these findings, it is estimated that there are approximately 1,800 children per million population with conductive causes of hearing impairment that could be treated or prevented through the provision of basic primary ear and hearing care services.

Table 8 Results of ear examination for people with bilateral severe/moderate hearing impairment

	%
External ear canal	
Inflammation	**3%**
Wax	**33%**
Foreign body	**1%**
Ear Drum	
Perforation	**45%**
Retraction	**1%**
Red and bulging	**2%**
Middle Ear	
Discharge	**33%**
No Symptoms	**25%**

NB: some children had more than one of these symptoms/conditions, hence summed totals equal more than 100%

Causes of Vision Impairment (VI)

Children with moderate/severe vision impairment in the better eye underwent an eye examination to determine the cause. Corneal opacity was the leading known cause (figure 2), responsible for just over a quarter of vision impairment (figure 2), followed by refractive error (16%), conditions of the whole eye (microphthalmus/anophthalmus) and un-operated cataract (10%).

Subdividing cause by age group shows that the proportion of childhood VI due to corneal opacity was higher (32%) among children aged <10 years compared to ≥10 years (18%).

In terms of treatment, these data suggest that approximately 60 children per million total population could benefit from refractive services and that 40 children per million total population need cataract surgery. Approximately 100 children per million population have corneal scars which could have been prevented through the provision of basic primary health services (to prevent Vitamin A and measles).

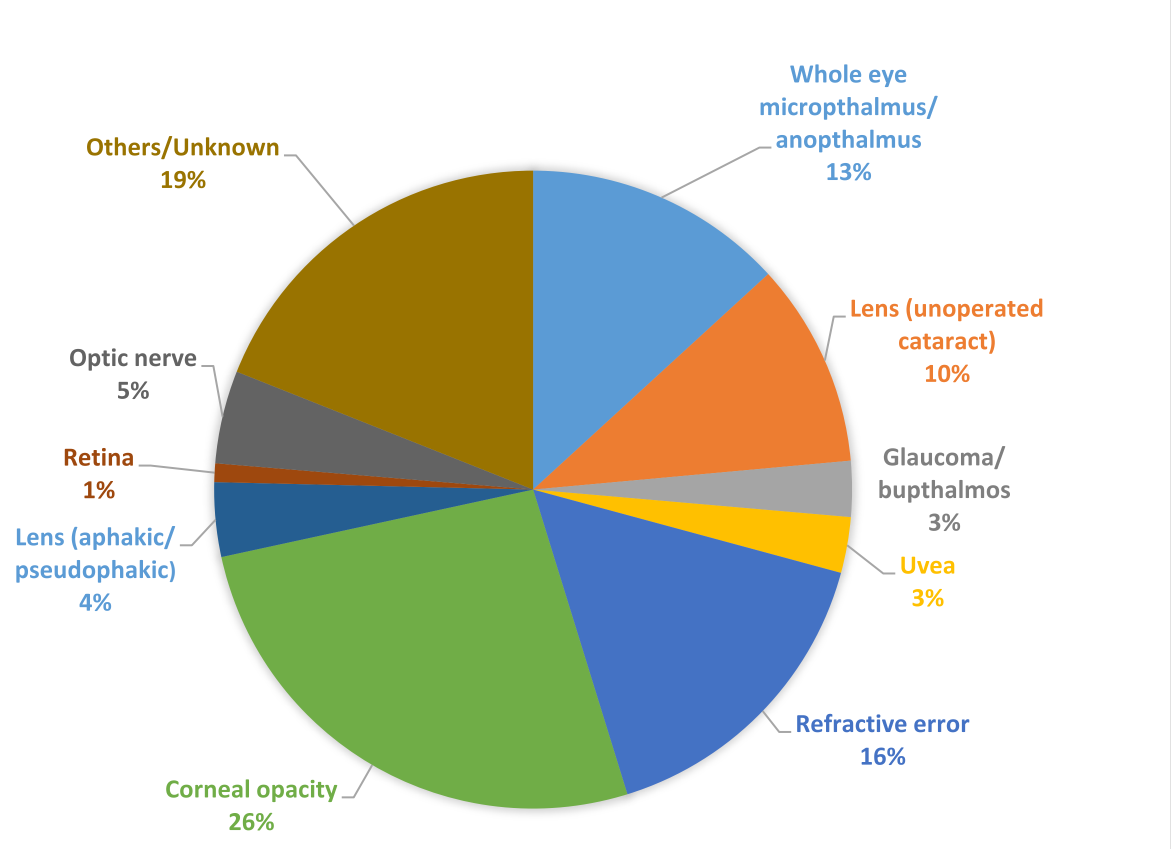


Figure 2: Causes of moderate/severe vision impairment

Intellectual impairment

Of the children identified as having intellectual impairment, 15% were diagnosed as having Cerebral Palsy, 14% microcephaly, 9% hydrocephaly and 6% had Down's Syndrome. Intellectual impairment was diagnosed by a set of screening questions (see Appendix 1). The proportion of children screening positive to each question is shown in figure 3 indicating a high frequency of both behavioural difficulties (e.g. making friends) as well as learning difficulties.

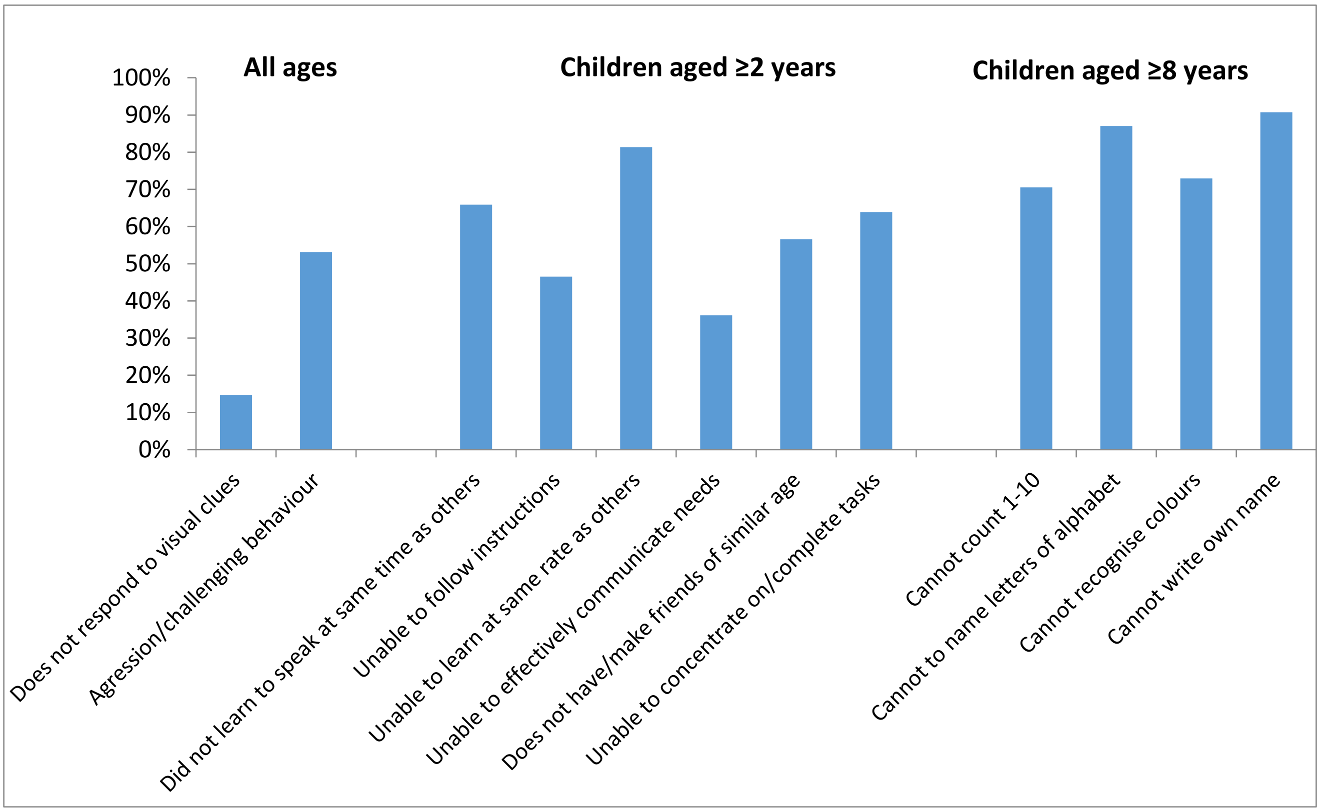


Figure 3 The proportion of children who screened positive to each question in the intellectual impairment screening tool

Table 9 presents the number of questions that children, defined as having intellectual impairment (according to the screening questionnaire), screened positive for (i.e. responded ‘no’ to the question) as an indication of the level of impairment. For children aged 2-7 years (for whom 8 questions were applicable), 61% screened positive on 3-5 questions, while 39% screened positive for 6-8 questions. For children aged 8 years and above (for whom 12 questions were applicable) nearly half (42%) screened positive for 3-5 questions, 36% for 6-8 questions and 22% screened positive for at least 9 questions.

Table 9: Number of questions children screened 'positive' for in the intellectual impairment questionnaire

Number of questions screened positive for*	Proportion of children aged 2-7 years	Proportion of children aged 8 years and above
3	14%	11%
4	21%	18%
5	25%	14%
6	12%	13%
7	17%	14%
8	9%	10%
9	-	9%
10	-	5%
11	-	7%
12	-	1%

*Number of questions for which respondent reported 'no' – indicating severity of intellectual impairment (see questionnaire in Appendix 1). Results restricted to those children who screened positive through the questionnaire. NB: 8 questions were asked for children aged 2-7 years and 12 questions for children aged 8 years and above

Epilepsy treatment history

Of the children confirmed as having epilepsy through the screening questionnaire, 80% were reported to have been seen by a medical person, but only half of the children were reported as currently taking medication for this condition.

Age, gender and school attendance by type of impairment/epilepsy

Table 10 presents the age and gender distribution by impairment type. For hearing, vision and intellectual impairment there was a slightly higher proportion of males than females (table 10), while for physical impairment and epilepsy the distribution was equal.

There was some variation in school attendance between the different groups of impairment/epilepsy (table 11). Compared to children with hearing impairments (9%) non-attendance at school was significantly higher ($p<0.001$) for children with other impairments/epilepsy (physical impairment: 17%, vision impairment: 19%, Epilepsy: 29%, intellectual impairment: 34% and multiple impairments: 62%). This difference remained significant with adjustment for age and gender.

Table 10: Age and gender distribution by type of impairment/epilepsy

	Physical impairment N (%)	Hearing impairment N (%)	Visual impairment N (%)	Intellectual impairment N (%)	Epilepsy N (%)	Total N (%)
Sex						
Male	426 (51%)	303 (54%)	59 (56%)	323 (58%)	233 (50%)	1117 (52%)
Female	414 (49%)	263 (46%)	46 (44%)	236 (42%)	229 (50%)	1014 (48%)
Age (yrs)						
0 to 4	328 (30%)	172 (23%)	33 (27%)	124 (17%)	73 (12%)	619 (23%)
5 to 10	335 (31%)	267 (36%)	41 (33%)	257 (36%)	194 (32%)	903 (34%)
10 to 14	275 (25%)	206 (28%)	32 (26%)	210 (29%)	172 (28%)	760 (28%)
15 to 18	150 (14%)	102 (14%)	18 (15%)	131 (18%)	167 (28%)	456 (17%)
Mean age (95% CI)	8.1 (7.8-8.5)	8.5 (8.1-8.8)	8.2 (7.4-9.1)	9.5 (9.1-9.8)	10.5 (10.1-19.9)	8.7 (8.6-8.9)

Table 11 School attendance by impairment/epilepsy type

Impairment/epilepsy group	Never attended school N (%)	Odds ratios adjusted for age and sex (95% CI)
Hearing impairment	40 (9%)	1.0
Physical impairment	76 (17%)	2.0 (1.3-3.0)
Vision impairment	12 (19%)	2.3 (1.1-4.5)
Epilepsy	81 (29%)	4.0 (2.6-6.1)
Intellectual impairment	82 (34%)	5.0 (3.3-7.6)
Multiple	161 (62%)	16.2 (10.7-24.5)

Reasons for non-attendance at the screening camps

Study population

A total of 212 households with 236 non-attending children (some households had more than one registered child) were interviewed (response rate 80%). Table 12 shows the age and gender distribution of the children included in the sample. This was very similar to that of children with confirmed impairments/epilepsy who attended the camps.

The vast majority of children in the sample of non-attenders (94%) aged 5 years and above were reported to have at least some problem with one of the Washington Group (WG) domains (table 13). Of the 12 who reported no problem, 8 were reported to have had seizures (not captured using the WG questionnaire). Using the WG definition of 'some problem with at least two domains or a lot of problem /cannot do with at least one domain' 63% of children were classified as having a disability.

Table 12 Age and gender distribution of 1)sample interviewed about non-attendance and 2)children attending camp confirmed as having an impairment/epilepsy

	Sample of children who did not attend screening camps N (%)	Children who did attend and had impairment/epilepsy %
Age (years)		
0-4	39 (17%)	23%
5-9	83 (35%)	34%
10-14	80 (34%)	28%
15-18	33 (14%)	17%
Sex		
Males	124 (53%)	52%
Females	112 (47%)	48%

Table 13 Disability status of children aged >5 years who did not attend the camps

	N (%)
No problem with any domains/no reported seizures	2 (1%)
No problem with any domains but reported seizures	8 (4%)
Some problem with one domain	56 (30%)
Some problem with at least two domains	50 (27%)
Extreme problem/cannot do with at least one domain	68 (36%)

*NB: These data are restricted to children aged 5 years and above as some of the questions are not applicable to the younger age group.

Reported reasons for non-attendance

In terms of reasons for non-attendance, nearly a third of the sample reported they did not know about the camps and 15% reported not knowing the time or date of the camp(table 14). Barriers to accessing the camps were reported by over a third of respondents (36%) including the distance (17%), financial barriers (11%) and physical barriers. Personal family reasons were reported by 44% of the respondents, including being too busy (19%) and the child or other household member being ill (16%).

Table 14 Reasons given for not attending screening camps

Reason	N	%
Organisation/communication reasons		
Did not know about camp	65	31%
Did not know time/date of camp	32	15%
Attended camp too late / not examined	8	4%
Forgot time/location of camp	2	1%
Access difficulties		
Camp too far	35	17%
No money – transport	18	8%
No money - incidentals (food en route, soap to wash clothes)	7	3%
Physical difficulties (e.g. child too heavy to carry, mother pregnant)	12	6%
No transport available	4	2%
Personal family reasons		
Busy (working, away, attending family/village events)	40	19%
Child/household member ill.	33	16%
No one to take child	13	6%
Didn't want child to miss school	6	3%
Other	10	5%

DISCUSSION

This was the first study to use the KIM to estimate the prevalence of different impairments and epilepsy among children in an African country. The method successfully identified a large group of more than 2,500 children with different types of impairments. In addition to providing much needed data on child disability - currently lacking in the region and in LMIC generally - the study also had an important capacity building and disability awareness raising component, training 500 KIs from the community in identification of disability in children as well as linking with a network of referral services in the study area.

The estimated prevalence for any impairment/epilepsy in this study was 17.3/1,000 children. This is higher than found in the previous study using the KIM in Bangladesh (9.0/1,000) and Pakistan (5.4/1,000)[7], which may be for a number of reasons. Children with intellectual impairment were included in the current study, but not in Bangladesh or Pakistan. Furthermore, there was a higher prevalence of hearing impairment in the current study, which was acknowledged as a probable underestimate in Bangladesh and Pakistan. Malawi is also substantially poorer. This may be reflected in a higher prevalence of childhood disability given that conditions associated with poverty (e.g. lack of access to health care, water and sanitation and education, poor nutritional status and poor living conditions) can increase the risk of developing chronic impairments.[1]

Few other studies of multiple impairments/disability in children are available for comparison. The 2008 Malawi Housing and Population Census which classified disability into one of five types (hearing, seeing, walking, speaking and other) estimated childhood disability prevalence to be 24/1,000.[12] The UNICEF Multiple Indicator Cluster Surveys conducted in 26 countries using the Ten Question screening tool found that between 14-36% of children screened positive, considerably higher than our estimates.[2] However, this tool is acknowledged to have a relatively low positive predictive value, identifying children who with further examination are found not to have a disability, and including children with “milder” disabilities.

The prevalence estimates for different impairments were generally comparable to other studies in LMIC, lending weight to the reliability of our findings. Physical impairment was the most common impairment type identified, which corresponds with previous studies. For example, a recent analysis of data on children sponsored by PLAN International found physical impairment to be the most commonly reported type of disability among children with disabilities in the majority of the 30 LMIC included in the study.[3] In accordance with previous studies in low income countries, Cerebral Palsy was the single most common underlying health condition.[7] The prevalence of visual impairment was similar to estimates from previous studies using KIM in

Uganda (0.7/1,000) and Ethiopia (0.6/1,000).[19, 20] The epilepsy prevalence in our study was within the range estimated in a systematic review of epilepsy in Sub-Saharan Africa.[13] The estimated prevalence of hearing impairment was lower than estimates produced for the Global Burden of Diseases study for Sub-Saharan Africa (19/1,000 for children aged 5-14 years), although as the authors acknowledge, these estimates are based on very limited population based data.[21]

Exclusion of children with disabilities from education is a widely reported concern with evidence from LMIC suggesting that primary school attendance and completion rates among children with disabilities are significantly lower compared to their non-disabled peers.[1, 3] In this study, the majority (73%) of children with disabilities were attending school. While this is encouraging, it does not tell us about the quality of education received by children with disabilities, which is often thought to be inadequate, or retention and completion rates.[22] Further work is needed in this setting to explore and understand the educational experiences of children with disabilities and the extent to which they are included in comparison to their non-disabled peers. Furthermore, the fact that nearly 30% of children with disabilities of school-going age were not attending school and the reasons for this should not be ignored. Illness was reported as the most common reason. Environmental and attitudinal barriers were also reported. These need to be addressed through policy and school-level changes in order to achieve the inclusion of children with disabilities in education which is so important for their future social and economic well-being.

School attendance varied by type of impairment. As has been found in previous studies[1, 3], children with intellectual impairments were the least likely to attend school. Attendance was also lower among children with epilepsy supporting previous evidence of exclusion from education for children with this condition.[14]

How can this information be used?

Data generated by this study can be used to inform service planning and for advocacy for children with disabilities in Malawi. For example we estimate that around 2,100 children per million population in Malawi are in need of physical or occupational therapy, and that 300 children per million population could benefit from a wheelchair, but the data suggest that few children requiring these services are currently receiving them. A country level situational analysis of availability of facilities, resources and personnel to meet these needs would be beneficial for informing planning of future service provision. A shortfall of physiotherapists – only 29 in the country (personal communication) - is a recognised challenge in this setting. These data can be used by the government and the medical school which started a training course for physiotherapists four years ago to address the shortfall.

Hearing impairment was the second most common impairment type identified, estimated to affect approximately 2,500 children per million population. The study findings indicate that more than 75% of hearing impairment in children is attributable to conductive hearing loss caused by avoidable conditions such as acute and chronic middle ear infection and presence of wax. Such conditions can be prevented and treated through primary ear and hearing care services. However, these services are currently limited in Malawi[23] and there is an urgent need to increase the number of personnel trained in primary ear care in this setting. Potential strategies to address this gap which could be explored include the training of Health Surveillance Assistants (of which there are more than 10,000 in the country) in the delivery of primary ear and hearing care. A further priority is the provision of affordable hearing aids. According to the Ministry of Health's National Health Development Plan for Ear and Hearing Care report[23], hearing aid provision in the country is currently unreliable and heavily donor dependent, which needs to be addressed.

Only half of the children defined as having epilepsy in this study reported receiving any medication, even though 80% were reported to have seen a health care professional for their condition. The significant treatment gap for epilepsy has been reported in other settings[24] and has been attributed to poor supplies of medication, lack of trained health care staff, limited access to health facilities and stigma. Our study highlights the urgent need to explore and address the specific issues and barriers to treatment in this setting.

The data on aetiology of vision impairment is also useful for identifying treatment and rehabilitation needs. It is estimated that nearly 400 children per million population have visual impairment. Corneal opacities were the commonest cause of vision loss, as is typical in very low income settings.[20] Leading causes of corneal scars include Vitamin A deficiency and measles which can be prevented through provision of basic primary health care services and are therefore an urgent priority in Malawi. The proportion of visual impairment due to corneal scar was lower among the children aged <10 years (18%) compared to those ≥10 years (32%) suggesting some positive effect of measles immunization / vitamin A supplementation programmes in this setting. However at 18% it was still high, indicating a need to strengthen and sustain these efforts. Refractive error was the second leading cause of vision impairment, highlighting a need for basic eye screening among children and provision of corrective eye glasses as appropriate, which could be integrated into school health programmes.[20] Early detection and good quality surgery are key in preventing vision loss from lens opacities, which were responsible for 14% of vision loss. Many of the children with visual impairment that is not amenable to treatment have some residual vision. Low vision services to maximise functioning would be of significant benefit to these children.

Intellectual impairment is a relatively neglected area in LMIC with services, trained personnel and evidence on the effectiveness of interventions all sorely lacking.[25] There is some evidence to suggest that provision of psychosocial services by non-specialist providers (e.g. teachers and parents) may be effective for children with intellectual impairment where specialist services are unavailable.[25] This approach deserves exploration in Malawi given the relatively high number of children experiencing intellectual disability in this study. Furthermore, parent supported interventions such as for Cerebral Palsy can also fill an important gap.[9]

How well did the KIM work?

Challenges and limitations

The number of children listed by the KIs in this setting was considerably higher than anticipated based on expected prevalence of impairments and epilepsy. This led to logistical challenges in the early stages of the project and required additional camps to be organised. However, a large proportion (61%) of the children referred by KIs, did not subsequently screen positive according to the study definitions of impairment and epilepsy. A similar pattern was observed using KIM in Bangladesh, which also had relatively low specificity. Reasons for this are unclear. This study had a relatively narrow focus on moderate and severe impairments and epilepsy. Some of the children listed by KIs may have had mild impairments, unilateral hearing/vision impairments or other health conditions temporarily affecting body function/structures. It is also possible that given limited access to health care services among this population, children were referred by KIs to the camps because it was an opportunity to see a health professional for another health problem/acute condition. While preferable to under-referring of children with disabilities, the over-referral of children in this method does have time, resource and efficiency implications and this deserves attention in future studies using KIM.

Surprisingly, nearly 50% of the children listed by KIs did not attend the camps, whereas the earlier KIMs in Bangladesh and Pakistan noted that the vast majority of children attended. Reasons given for this included organisational issues (i.e. dissemination of information about the camps), barriers to attending the camp (distance, time and cost) and personal factors (lack of time and illness). The importance of effective and timely communication with KIs should be noted for future studies using KIM. A key recommendation would be to determine the time, date and location of the camps in advance and disseminate this information during the trainings. In addition, monitoring of dissemination of information by KIs to households prior to the camps may be warranted. Consideration regarding camp locations and feasibility of travel for carers and their children with disabilities is also warranted in a country like Malawi with its varied topography and limited road/transport infrastructure.

A consequence of this low attendance was the need to rely on assumptions about the prevalence of disability among the non-attenders in order to calculate the overall prevalence of impairment/epilepsy in the study areas.

The study focussed only on clinician assessed impairment and epilepsy. An advantage of this approach is that the information generated can inform specific medical and rehabilitation services. However, it is acknowledged that it provides only part of the picture of disability because it does not capture an individual's functioning and participation which can vary substantially depending on a range of internal and external factors.

Strengths

Using the KIM this study identified a large group of children with disabilities in Malawi and makes an important contribution to the limited data available on the epidemiology of child disability in LMIC. Intellectual impairment was included in this study, which has been lacking from previous KIM projects for child disability and for which data in Africa are generally scarce. The data on prevalence and aetiology for the individual impairment groups and epilepsy were comparable with the few previous studies that have been undertaken in LMIC lending weight to the reliability of the findings. The study findings can be used for planning of services, advocacy and for guiding future research with children with disabilities.

Community involvement is an important strength of this study methodology. Five hundred KIs from the community underwent training which included disability awareness as well as the identification of children with specific impairments/epilepsy. An additional benefit of the KIM is the mapping of services at the start of the project. These were predominantly health and rehabilitation services and highlighted both the strengths as well as the gaps of services available for children with disabilities in the areas. Further, the study has provided data for educational services in terms of estimates of school attendance among the different impairment groups. This can be used to inform the kind of accessibility features needed in order to increase school attendance by children with the particular types of impairments who currently face the most significant barriers to education. Finally, the value of the KIM was observed by other disability service providers in Malawi who are keen to use the method for their own screening/baseline purposes.

Conclusions

1. The KIM successfully identified more than 2,500 children with different types of disability in two districts in Malawi.
2. The estimated prevalence of impairments/epilepsy was 17.3/1,000. Physical impairment was the most common disability type (39%), followed by bilateral hearing impairment (27%), intellectual impairment (26%), epilepsy (22%) and bilateral vision impairment (4%). Fourteen percent of the children had multiple impairments.
3. The KIM helped to identify service needs for children with disabilities including the following:
    - There are an estimated 3,520 children per million population with physical impairments in this setting of whom 2,100 children per million population could benefit from physiotherapy or occupational therapy and 300 per million of whom are in need of a wheelchair.
    - There are an estimated to be approximately 1,800 children per million population with hearing impairment from avoidable causes that could be prevented or treated though provision of basic primary level ear and hearing care.
    - There is a significant treatment gap for epilepsy: only 50% of children with epilepsy were reported to be receiving treatment.
    - Corneal opacity was the leading cause of vision loss, highlighting a need to strengthen and sustain measles immunization / vitamin A supplementation programmes.
    - There are estimated to be approximately 2,100 children per million with intellectual impairment, but relevant services in this setting are considered lacking.
4. As well as providing data on child disability that can be used for advocacy and to inform planning, this method also has an important capacity building and disability awareness raising component with the training of 500 KIs from the community in disability awareness and mapping of medical and rehabilitation services.
5. Attendance at the camps was relatively low and this needs to be addressed in future applications of the KIM. Lessons learnt include ensuring timely communication with KIs regarding camp details and the need for consideration to the physical and financial accessibility of the camps in different settings.
6. Children with impairments/epilepsy screened at the camps were referred to medical and rehabilitation services. Further work to determine the uptake and experiences of these services is needed.
7. Nearly three-quarters of children with disabilities were attending school, although this varied by impairment type. However, information is needed on the educational

experiences of children with disabilities and the extent to which they are included in comparison to their non-disabled peers.

Recommendations

1. To use the results from the study to plan and advocate for services for children with disabilities, in particular for:
    - Physiotherapy and occupational therapy for children with physical impairments.
    - Development of basic primary level ear and hearing care.
    - Provision of medication for children with epilepsy.
    - Strengthening measles immunization / vitamin A supplementation programmes.
    - Developing services for children with intellectual impairment.
2. To consider modifying the KIM to enable screening of children in their households to reduce loss to follow up.
3. To increase attention on improving school attendance and assess the quality of education among children with disabilities.

APPENDIX 1. Data Collection Forms

Intake

Date (day/month/year): ___ ___ / ___ ___ / ___ ___

Consent has been given by the parent/guardian? Yes ☐ No ☐

Child agrees to participate? Yes ☐ 0 No ☐ 1

District: Ntcheu ☐ 0 Thyolo ☐ 1 Camp Number ☐

Camp location: ____

Child's name: ____

Child DOB (day/month/year): ___ ___ / ___ ___ / ___ ___

Must be born in 1995 or later
(17 years or under)

Name of home village: ____

Guardian's name: ____

Guardian's relationship to child: ____

Telephone number (if any): ____________________________

Name of mother/primary caregiver: ____

Literacy of primary caregiver: __________

Illiterate	0
Read/ write	1
Primary	2
Secondary	3
Post-secondary	4

Estimated family income (monthly)

Less than 12,000	☐	0
12,000-30,000	☐	1
20,000-30,000	☐	2
50,000-150,000	☐	3
Above 150,000	☐	4

Have referrals been recommended in health passport? Yes ☐ 0 No ☐ 1

If yes, where was child referred to and for what service(s)?

Has child ever received treatment/support for their condition in the past? Yes ☐ 0 No ☐ 1

Unknown ☐ 3

Education

For children 6 years and above ONLY

1 Is the child currently enrolled in school?	No	☐	0	Go to Q7
	Yes	☐	1	Go to Q2

2 Level of school currently enrolled in:	Nusery	☐	0
	Primary	☐	1
	Secondary	☐	2

3 Is the school you are currently enrolled in private or public?	Public	☐	0
	Private secular	☐	1
	Private religious	☐	2

4 Is it disability-specific?	No it's a regular "mainstream" school	☐	0	
	No it's a regular school but with a disability resource centre attached	☐	1	
	No it's a regular school but a resource teacher visits from time to time	☐	2	
	Yes is a "special" school for disabled children	☐	3	If yes: Is is a school for the deaf? Y ☐ N ☐ Is it a school for the blind? Y ☐ N ☐

5 In the last month how many days have you missed from school? Enter number of days ☐

6 Have you ever repeated a grade at school?	Yes	☐	0	Go to Q6
	No	☐	1	End of Education questions. Proceed to next section.

7 If yes, how many times have you repeated a grade at school Enter numeric value: ____________

Questions below only for those children not currently enrolled in school

8 If not currently enrolled, have you ever attended school?	Yes	☐	0
	No	☐	1

9 If yes, what is the highest grade you completed? ____________

10 If you have never attended/are currently not attending school, what is the reason?	Not enough money	☐	0	
	Lack of interest to go to school	☐	1	
	Illness (less than one month)	☐	2	
	Illness (one month or more)	☐	3	
	Because of disability- refused by school	☐	4	
	Because of disability- negative attitudes of other students	☐	5	
	School not accessible	☐	6	
	Other	☐	7	Please specify: ____________

Screening Questions

For all children:

1 Does your child have problems seeing?	Yes	☐	0	If yes, refer to EYES
	No	☐	1	
2 Does your child have problems hearing?	Yes	☐	0	If yes, refer to ENT
	No	☐	1	
3 Does your child ever have fits/convulsions?	Yes	☐	0	If yes, refer to Epilepsy
	No	☐	1	

In cases of apparent CEREBRAL PALSY:
Refer to ORTHOPAEDICS
and INTELLECTUAL IMPAIRMENT
and EPILEPSY (if fits are reported)
and other as required

All albino children should be seen by
EYES as well as other modalities,
based on parental concern

For children aged 2 years and above:

4 Does your child have a problem with their body that makes t hard for them to do daily activities like feeding or washing?	Yes	☐	0	If yes, refer to orthopaedics
	No	☐	1	and/or intellectual impairment
5 Does your child have probelms walking?	Yes	☐	0	If yes, refer to orthopaedics
	No	☐	1	
6 Does your child have problems talking?	Yes	☐	0	If yes, refer to ENT
	No	☐	1	*and* intellectual impairment
7 Does your child have problems with learning / understanding?	Yes	☐	0	If yes, refer to intellectual
	No	☐	1	impairment

All children with apparent
DOWN SYNDROME
should be seen by ENT
as well as INTELLECTUAL
IMPAIRMENT

Epilepsy

1 Is presence of epilepsy suspected in this child? Yes ☐ 0 No ☐ 1
If no, proceed to next section. If yes, complete questions below.

2 Does your child ever have/had fits/ become rigid or lose consciousness? Yes ☐ 0 No ☐ 1

3 Did your child ever have spasm/jerky movements of arms/legs/ whole body? Yes ☐ 0 No ☐ 1

4 Was there frothing at the mouth during one or more episodes? Yes ☐ 0 No ☐ 1

5 How many episodes in the last 3 months? 0 ☐ 1 to 2 ☐ 3 to 10 ☐ >10 ☐

6 How many episodes over the past year? 0 ☐ 1 to 2 ☐ 3 to 10 ☐ >10 ☐

7 Has the child been seen by a medical person for this problem? Yes ☐ 0 No ☐ 1 Unknown ☐ 3

8 Does the child have medication for this problem? Yes ☐ 0 No ☐ 1 Unknown ☐ 3

9 Do you confirm suspicion of epilepsy in this child? Yes ☐ 0 No ☐ 1

10 Ntcheu only: Follow up by CBR programme recommended? Yes ☐ 0 No ☐ 1

11 Follow up at QECH paediatric department recommended? Yes ☐ 0 No ☐ 1

12 Referral made, explained, and recorded in HEALTH PASSPORT Yes ☐ 0 No ☐ 1

____

Visual Impairment

1 Do the child's eyes look abnormal in any way ? Yes ☐ 0 No ☐ 1 Unable to examine ☐ 3

2 Does the caregiver think that the child has serious problems in seeing? Yes ☐ 0 No ☐ 1

If the child 5 years or younger

3 Can the child look at and follow a moving object? Yes ☐ 0 No ☐ 1 Unable to examine ☐ 3

4 Can the child count fingers from 6 metres with both eyes open? Yes ☐ 0 No ☐ 1 Unable to examine ☐ 3

Visual acuity

Note: Snellen's E chart to be used to assess visual acuity

5 **Presenting visual acuity Part 1**

MULTIPLE CHOICE (one choice only)

Can fix & Follow light (0-5 yrs)	☐	0
Cannot test but believe sighted	☐	1
Cannot test but believed blind	☐	2
Cannot see light in both eyes	☐	3
Can only see light in better eye	☐	4

6 **Presenting visual acuity Part 2**

6.1 Presenting visual acuity can be tested Yes [0] No [1]

6.2 Can see 6/60 in better eye Yes ☐ No ☐

6.3 Can see 5/60 in better eye Yes ☐ No ☐

6.4 Can see 4/60 in better eye Yes ☐ No ☐

6.4 Can see 3/60 in better eye Yes ☐ No ☐

7 **Pinhole visual acuity**

7 Can see 6/60 in better eye Yes ☐ No ☐

7 Can see 5/60 in better eye Yes ☐ No ☐

7 Can see 4/60 in better eye Yes ☐ No ☐

7 Can see 3/60 in better eye Yes ☐ No ☐

9 **Cause of blindness or severe visual impairment**

MULTIPLE CHOICE (choose one of 11 choices below)

Whole eye microphthalmos/anophthalmos (one or both eyes)	☐	00'
Lens (unoperated cataract in one or both eyes)	☐	01'
Glaucoma/ buphthalmos	☐	02'
Uvea (e.g. aniridia, uveitis)	☐	03'
Suspected uncorrected refractive error	☐	04'
Corneal opacity	☐	05'
Lens (aphakic or pseudophakic in both eyes)	☐	06'
Retina (dystrophy/detachment)-8; -9	☐	07'
Optic Nerve(atrophy/hypoplasia)	☐	08'
Cause unknown	☐	09'
Others	☐	10'

Other, please specify:

10 **Evidence exists to suggest presence of visual impairment** Yes ☐ No ☐

11 **Ntcheu only: Follow up by CBR programme recommended** Yes ☐ No ☐

12 **Follow up recommended?** Yes ☐ No ☐

HEARING IMPAIRMENT

Speech and Language

1 Is the child is 6 months old, or younger? Yes ☐ 0 No ☐ 1

If YES, proceed to Q 2; If no, proceed to Q 3

2 Does he/she have speech or vocalization? Yes ☐ 0 No ☐ 1

If YES, proceed to Q 6; If no, proceed to Q 7

3 Is the child 2 years old? Yes ☐ 0 No ☐ 1

If yes, proceed to Q 4; If not, proceed to Q 5

4 Can he/she say the names of familiar objects? Yes ☐ 0 No ☐ 1

If YES, proceed to Q 6; If no, proceed to Q 7

5 Can the child speak whole sentences like other children? Yes ☐ 0 No ☐ 1

If YES, proceed to Q 6; If no, proceed to Q 7

6 Is the child's speech / vocalisation in any way different from other children of same age? Yes ☐ 0 No ☐ 1

Ears

7 Is there any discharge or has the child had any discharge in the last year or so? Yes ☐ 0 No ☐ 1

8 Does the ear look abnormal in any way? Yes ☐ 0 No ☐ 1

Hearing

9 Is the child 2 years old or younger? Yes ☐ 0 No ☐ 1

If yes, proceed to Q 10; If no, proceed to Q 12

10 Does the child react to loud noises? Yes ☐ 0 No ☐ 1

11 If you speak normally to your child, does the child turn to look at you? Yes ☐ 0 No ☐ 1

From Q 11 skip to Q 13

12 Do you have to raise your voice to get your child's attention? Yes ☐ 0 No ☐ 1

13 Is there reason to suspect a (bilateral) disabling hearing impairment? Yes ☐ 0 No ☐ 1

Audiometry

Children can only be tested if they are 6 months old or older.

15 OAE Codes (for children 6 months - 4 years)

MULTIPLE CHOICE (one choice only)

Both ears pass ☐ 0
Right ear pass only ☐ 1
Left ear pass only ☐ 2
Both fail ☐ 3
Unable to test ☐ 4

16 Pure Tone Audiometry (for children from 5 to 17 years)

Enter Hearing Thresholds

Right	o.5 KHz	☐	1	1KHz	☐	2	2KHz	☐	3	4KHz	☐	4	No response	☐ 0
Left	o.5 KHz	☐	11	1KHz	☐	22	2KHz	☐	33	4KHz	☐	44	Not able to examine	☐ 5

17 Tympanometry

Type: (multiple choice, one choice)

A (normal) ☐ 0 B (OME) ☐ 1 C (xxx) ☐ 2

Basic Ear Assessment

18 Ear pain Yes ☐ 0 No ☐ 1

19 External Ear Canal

19.1	Inflammation	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2
19.2	Wax *If yes proceed to Q 19.2.1*	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2
19.3	Foreign body	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2
19.4	Ottorhoea (discharge)	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2

19.4.1, Discharge to be removed today? Yes ☐ No ☐

20 Ear Dum

20.1	Perforation	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2
20.2	Retraction	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2
20.3	Red and bulging	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2

21 Middle ear

Ottorhoea	Yes ☐ 0	No ☐ 1	Unable to examine ☐ 3	R ☐ 0	L ☐ 1	Both ☐ 2

22 Other cause Yes ☐ No ☐ If yes, please specify and note right / left: ____________________

23 Ntcheu only: Follow up by CBR programme recommended Yes ☐ 0 No ☐ 1

24 Follow up at QECH recommended Yes ☐ 0 No ☐ 1

25 Follow up at District hospital recommended? Yes ☐ 0 No ☐ 1

25 Referral made, explained, and recorded in HEALTH PASSPORT YES / NO

Intellectual disability screen

1 Does parent suspect any intellectual impairment / learning disability?
Yes ☐ 0 No ☐ 1

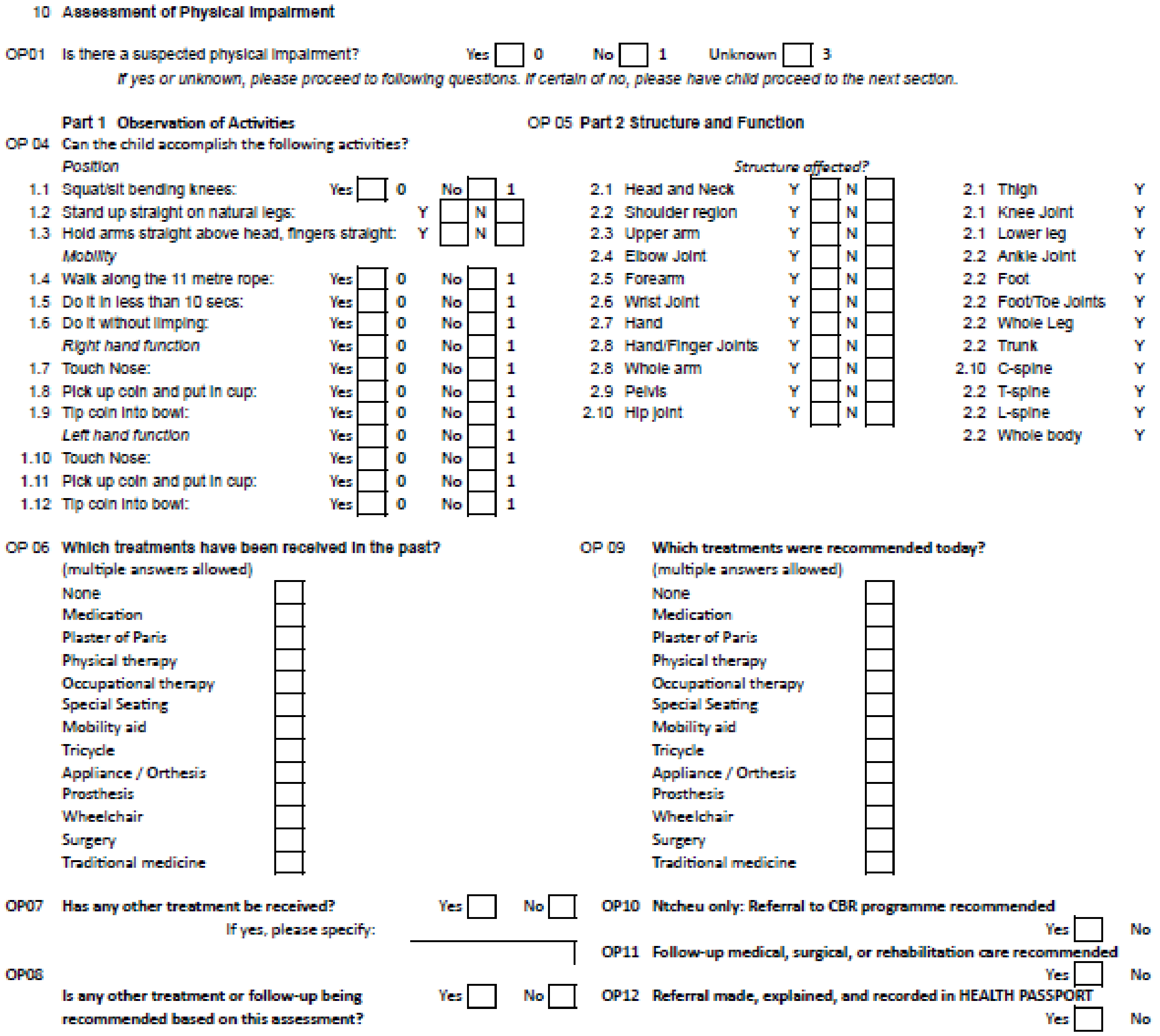
2 Do you (clinician) suspect any intellectual impairment / learning disability)?
If yes question 1 and/or question 2; please complete questions below. If no to both, proceed to next section. Yes ☐ 0 No ☐ 1

Screen for Intellectual impairment

3 For children of all ages:
3.1 Does the child respond to visual / gesture cues? Yes ☐ 0 No ☐ 1
3.2 Does the child have problems with aggression / unusual / challenging behaviour? No ☐ 0 Yes ☐ 1
For children *2 years* and above
3.3 Did the child learn to speak at the same time as others? Yes ☐ 0 No ☐ 1
3.4 Is the child able to follow instructions? Yes ☐ 0 No ☐ 1
3.5 Is the child able to learn at the same rate as others of the same age? Yes ☐ 0 No ☐ 1
3.6 Is the child able to effectively communicate needs? Yes ☐ 0 No ☐ 1
3.7 Does the child have or make friends of a similar age? Yes ☐ 0 No ☐ 1
3.8 Is the child able to concentrate on and complete a given task? Yes ☐ 0 No ☐ 1
For children *8 years* and above
3.9 Is the child able to count 1 – 10? Yes ☐ 0 No ☐ 1
3.10. Is the child able to name letters of the alphabet? Yes ☐ 0 No ☐ 1
3.11 Does the child recognise colours? Yes ☐ 0 No ☐ 1
3.12 Is the child able to write own name? Yes ☐ 0 No ☐ 1

4 Is presence of moderate to severe intellectual impairment suspected? YES / NO
NOTE: *Must have responded* *__least__* *3 of above questions in right-hand column ('no' except for 3.2 which is 'yes')* Yes ☐ 0 No ☐ 1

5 Ntcheu only: Follow up by CBR programme recommended? Yes ☐ 0 No ☐ 1
6 Follow up at QECH paediatric department and occupational therapy clinic recommended? Yes ☐ 0 No ☐ 1
7 If YES, has referral been made, explained, and recorded in HEALTH PASSPORT? Yes ☐ 0 No ☐ 1



10 Assessment of Physical Impairment

OP01 Is there a suspected physical impairment? Yes ☐ 0 No ☐ 1 Unknown ☐ 3

If yes or unknown, please proceed to following questions. If certain of no, please have child proceed to the next section.

Part 1 Observation of Activities

OP 04 Can the child accomplish the following activities?

	Position					
1.1	Squat/sit bending knees:	Yes ☐	0	No ☐	1	
1.2	Stand up straight on natural legs:			Y ☐	N ☐	
1.3	Hold arms straight above head, fingers straight:			Y ☐	N ☐	
	Mobility					
1.4	Walk along the 11 metre rope:	Yes ☐	0	No ☐	1	
1.5	Do it in less than 10 secs:	Yes ☐	0	No ☐	1	
1.6	Do it without limping:	Yes ☐	0	No ☐	1	
	Right hand function	Yes ☐	0	No ☐	1	
1.7	Touch Nose:	Yes ☐	0	No ☐	1	
1.8	Pick up coin and put in cup:	Yes ☐	0	No ☐	1	
1.9	Tip coin into bowl:	Yes ☐	0	No ☐	1	
	Left hand function	Yes ☐	0	No ☐	1	
1.10	Touch Nose:	Yes ☐	0	No ☐	1	
1.11	Pick up coin and put in cup:	Yes ☐	0	No ☐	1	
1.12	Tip coin into bowl:	Yes ☐	0	No ☐	1	

OP 05 **Part 2 Structure and Function**

Structure affected?

2.1	Head and Neck	Y ☐	N ☐	2.1	Thigh	Y
2.2	Shoulder region	Y ☐	N ☐	2.1	Knee Joint	Y
2.3	Upper arm	Y ☐	N ☐	2.1	Lower leg	Y
2.4	Elbow Joint	Y ☐	N ☐	2.2	Ankle Joint	Y
2.5	Forearm	Y ☐	N ☐	2.2	Foot	Y
2.6	Wrist Joint	Y ☐	N ☐	2.2	Foot/Toe Joints	Y
2.7	Hand	Y ☐	N ☐	2.2	Whole Leg	Y
2.8	Hand/Finger Joints	Y ☐	N ☐	2.2	Trunk	Y
2.8	Whole arm	Y ☐	N ☐	2.10	C-spine	Y
2.9	Pelvis	Y ☐	N ☐	2.2	T-spine	Y
2.10	Hip joint	Y ☐	N ☐	2.2	L-spine	Y
				2.2	Whole body	Y

OP 06 **Which treatments have been received in the past?**
(multiple answers allowed)

None ☐
Medication ☐
Plaster of Paris ☐
Physical therapy ☐
Occupational therapy ☐
Special Seating ☐
Mobility aid ☐
Tricycle ☐
Appliance / Orthesis ☐
Prosthesis ☐
Wheelchair ☐
Surgery ☐
Traditional medicine ☐

OP 09 **Which treatments were recommended today?**
(multiple answers allowed)

None ☐
Medication ☐
Plaster of Paris ☐
Physical therapy ☐
Occupational therapy ☐
Special Seating ☐
Mobility aid ☐
Tricycle ☐
Appliance / Orthesis ☐
Prosthesis ☐
Wheelchair ☐
Surgery ☐
Traditional medicine ☐

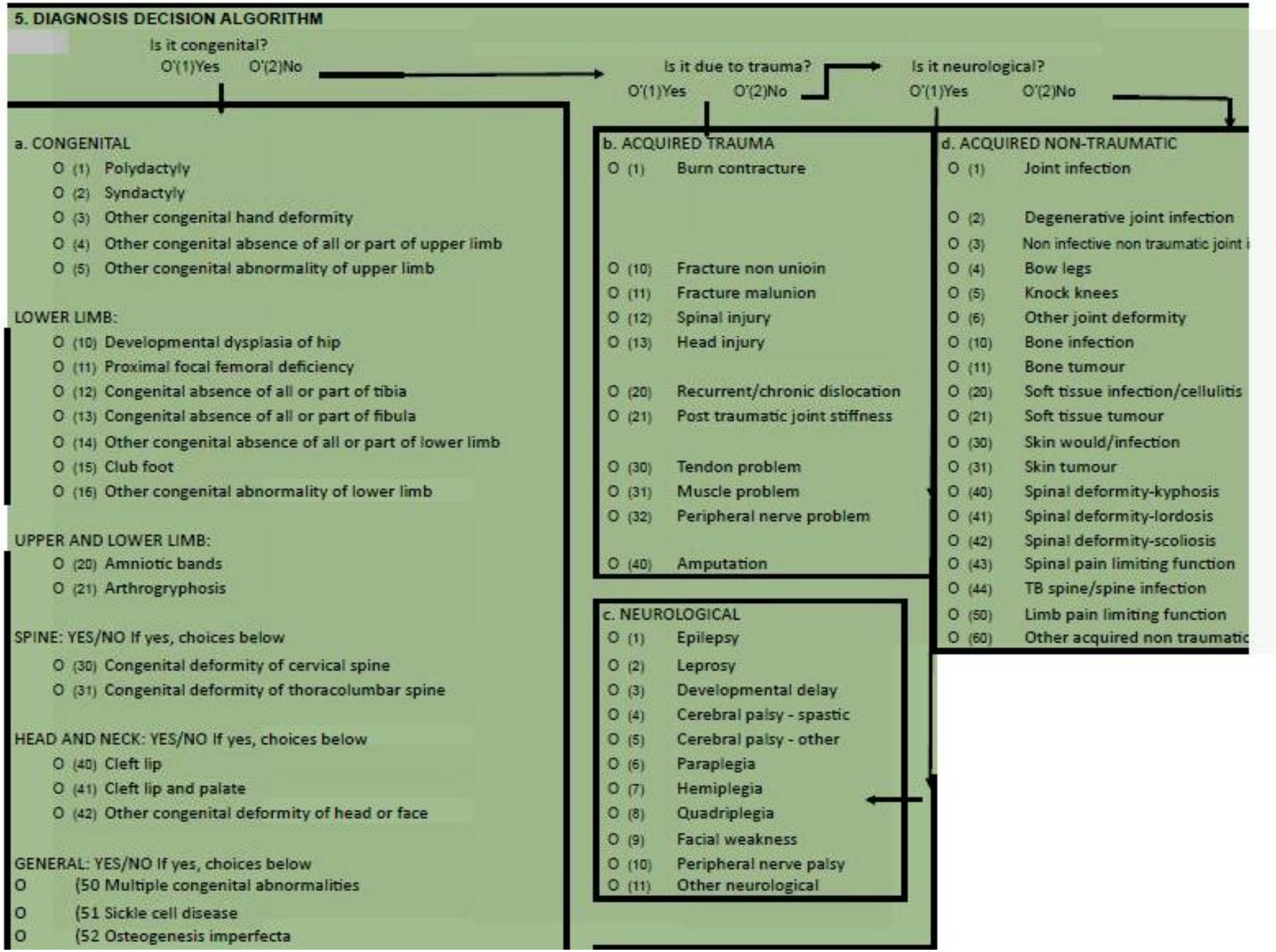
OP07 **Has any other treatment be received?** Yes ☐ No ☐
If yes, please specify: ____________________

OP08 **Is any other treatment or follow-up being recommended based on this assessment?** Yes ☐ No ☐

OP10 **Ntcheu only: Referral to CBR programme recommended** Yes ☐ No

OP11 **Follow-up medical, surgical, or rehabilitation care recommended** Yes ☐ No

OP12 **Referral made, explained, and recorded in HEALTH PASSPORT** Yes ☐ No



5. DIAGNOSIS DECISION ALGORITHM

Is it congenital?
○(1)Yes ○(2)No

Is it due to trauma?
○(1)Yes ○(2)No

Is it neurological?
○(1)Yes ○(2)No

a. CONGENITAL

- ○ (1) Polydactyly
- ○ (2) Syndactyly
- ○ (3) Other congenital hand deformity
- ○ (4) Other congenital absence of all or part of upper limb
- ○ (5) Other congenital abnormality of upper limb

LOWER LIMB:

- ○ (10) Developmental dysplasia of hip
- ○ (11) Proximal focal femoral deficiency
- ○ (12) Congenital absence of all or part of tibia
- ○ (13) Congenital absence of all or part of fibula
- ○ (14) Other congenital absence of all or part of lower limb
- ○ (15) Club foot
- ○ (16) Other congenital abnormality of lower limb

UPPER AND LOWER LIMB:

- ○ (20) Amniotic bands
- ○ (21) Arthrogryphosis

SPINE: YES/NO If yes, choices below

- ○ (30) Congenital deformity of cervical spine
- ○ (31) Congenital deformity of thoracolumbar spine

HEAD AND NECK: YES/NO If yes, choices below

- ○ (40) Cleft lip
- ○ (41) Cleft lip and palate
- ○ (42) Other congenital deformity of head or face

GENERAL: YES/NO If yes, choices below

- ○ (50 Multiple congenital abnormalities
- ○ (51 Sickle cell disease
- ○ (52 Osteogenesis imperfecta

b. ACQUIRED TRAUMA

- ○ (1) Burn contracture
- ○ (10) Fracture non unioin
- ○ (11) Fracture malunion
- ○ (12) Spinal injury
- ○ (13) Head injury
- ○ (20) Recurrent/chronic dislocation
- ○ (21) Post traumatic joint stiffness
- ○ (30) Tendon problem
- ○ (31) Muscle problem
- ○ (32) Peripheral nerve problem
- ○ (40) Amputation

c. NEUROLOGICAL

- ○ (1) Epilepsy
- ○ (2) Leprosy
- ○ (3) Developmental delay
- ○ (4) Cerebral palsy - spastic
- ○ (5) Cerebral palsy - other
- ○ (6) Paraplegia
- ○ (7) Hemiplegia
- ○ (8) Quadriplegia
- ○ (9) Facial weakness
- ○ (10) Peripheral nerve palsy
- ○ (11) Other neurological

d. ACQUIRED NON-TRAUMATIC

- ○ (1) Joint infection
- ○ (2) Degenerative joint infection
- ○ (3) Non infective non traumatic joint
- ○ (4) Bow legs
- ○ (5) Knock knees
- ○ (6) Other joint deformity
- ○ (10) Bone infection
- ○ (11) Bone tumour
- ○ (20) Soft tissue infection/cellulitis
- ○ (21) Soft tissue tumour
- ○ (30) Skin would/infection
- ○ (31) Skin tumour
- ○ (40) Spinal deformity-kyphosis
- ○ (41) Spinal deformity-lordosis
- ○ (42) Spinal deformity-scoliosis
- ○ (43) Spinal pain limiting function
- ○ (44) TB spine/spine infection
- ○ (50) Limb pain limiting function
- ○ (60) Other acquired non traumatic

APPENDIX 2 – Calculations of adjusted prevalence estimates

Table 1: Estimated the number of non-attending children with disability

Total no children registered by KI	15,000
Total no children who attended camps	7,220
Estimated number of non-attenders	7,780
Number of children attending camp with confirmed disability	2,788
Proportion of attenders with disability	39%
Estimated no non-attenders with disability (39% of 7,780)	3,034
Sensitivity analysis	
Estimated non-attenders with disability: lower (29% of 7,780)	2,256
Estimated no non-attenders with disability: higher (49% of 7,780)	3,812

Table 2. Total study population estimates

	Proportion among non-attenders	No. non-attenders with each impairment (RANGE*)	No attenders with each impairment	Estimated total in study district (RANGE)*	Estimated population size	Prevalence per 1000 (RANGE*)
Physical impairment	39%	1,183 (880-1,487)	1094	2,247 (1,974-2,581)	338,235	6.7 (5.8-7.6)
Hearing impairment	27%	819 (609-1,029)	752	1,550 (1,361-1,781)	338,235	4.6 (4.0-5.3)
Epilepsy	22%	667 (496-839)	608	1,258 (1,104-1,447)	338,235	3.8 (3.3-4.3)
Intellectual impairment	24%	728 (541-915)	724	1,452 (1,265-1,639)	338,235	4.3 (3.5-4.7)
Visual impairment	4%	121 (90-152)-	125	243 (215-277)	338,235	0.7 (0.7-0.8)
Multiple impairments	14%	425 (316-534)	392	806 (708-926)	338,235	2.4 (2.1-2.7)
Any impairment	100%	3,034 (2,256-3,812)	2788	5,844 (5,044-6,600)	338,235	17.3 (15.0-19.6)

*RANGE based on a sensitivity analysis assuming first that the prevalence was 10% lower among the non-examined children, and then that it was 10% higher

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