



The Malawi Key Informant Child Disability Project - Summary Report



The Key Informant Method (KIM) project in Malawi was implemented by the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine and the University of Malawi and funded by CBM, COSECSA Oxford Orthopaedic Link, Cure International UK, Fight for Sight and the Liliane Foundation



Background to the study

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 (Key Informants, KIs) to identify local children who may have disabilities, who are then screened by medical professionals and referred for appropriate health and rehabilitation interventions. The method offers an alternative to population-based surveys of disability in children, which can be costly and time consuming.

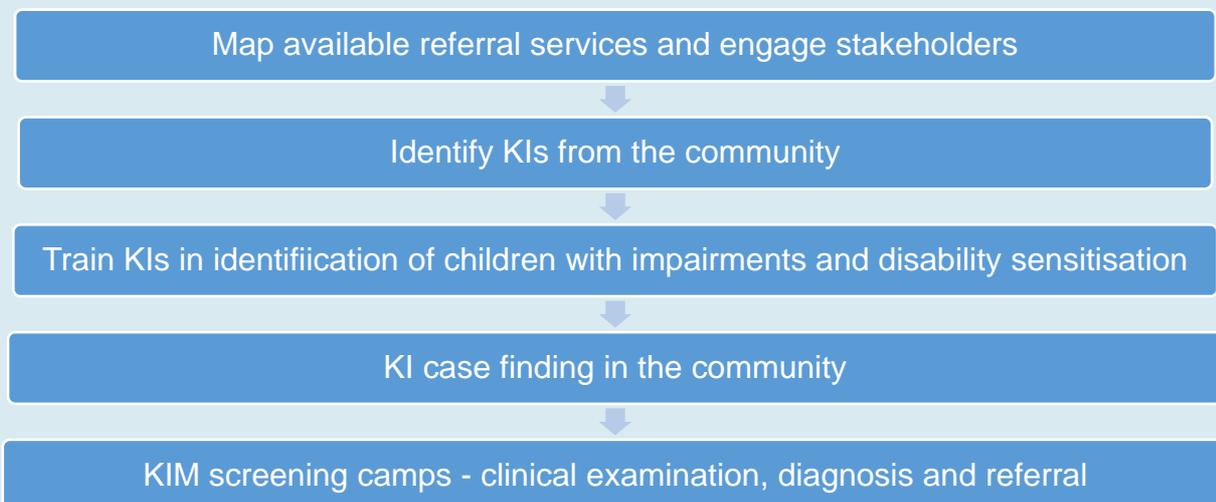
Aim and objectives

Aim: To use the KIM to estimate the prevalence of moderate or severe physical, sensory and intellectual impairments and epilepsy among children in Ntcheu and Thyolo districts, Malawi.

Objectives:

- To estimate the prevalence and cause of moderate/severe physical, vision, hearing and intellectual impairment and epilepsy among children under 18 years.
- 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 area who could be included in future research.

The Key Informant Method Overview



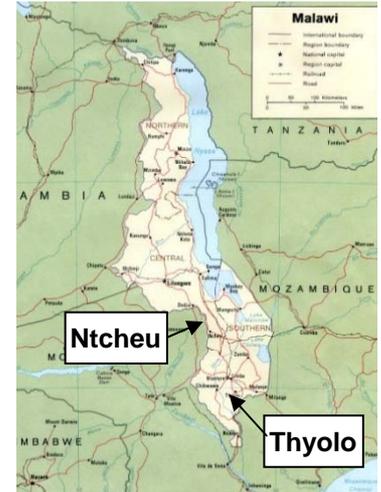
Study setting

Thyolo (Southern region) and Ntcheu (Central region). In each district four out of the eight Traditional Authorities were included (total estimated study population 338,235 children).

Definitions

This project focused on the following impairments/health conditions and inclusion criteria (in line with WHO recommendations):

- Moderate/severe hearing impairment: Presenting hearing >35 dBHL in both ears, or failure of Otoacoustic Emission test in both ears.
- Moderate/severe physical impairment: Physical impairment lasting >1 month affecting functioning based on observation of activities and physical examination.
- Moderate/severe vision impairment: Presenting visual acuity $<6/60$ in both eyes.
- Intellectual impairment: Responds 'no' to at least 3 of the age-relevant screening questions and/or has Down's Syndrome, microcephaly or hydrocephaly.
- Epilepsy: Clinician confirmed based on responses to screening questions.



KI training

- KIs were identified by Area Coordinators from existing groups of community volunteers who assist with public health campaigns and community mobilisations.
- 250 KIs per district (Thyolo and Ntcheu) underwent training in the following:
 - disability sensitisation
 - identification of the impairments included in the study
 - case finding methods
 - procedures for the screening camps
- After training KIs were given 3-6 weeks to identify children with the impairments included in the study and invite them together with a guardian to attend a screening camp



Screening camps

33 Screening camps were held across the two study districts. The screening camp teams were comprised of an orthopaedic clinical officer, ophthalmic clinical officer, Ear Nose and Throat clinical officer, audiologist, rehabilitation technician, social worker and two nurses.

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 17.3/1000 children (Table 1).
- Physical impairment (39%) was the 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. Attendance varied by impairment type and was lowest among children with multiple impairments (38%).

Figure 1. Number of children identified by KIs and screened at camps

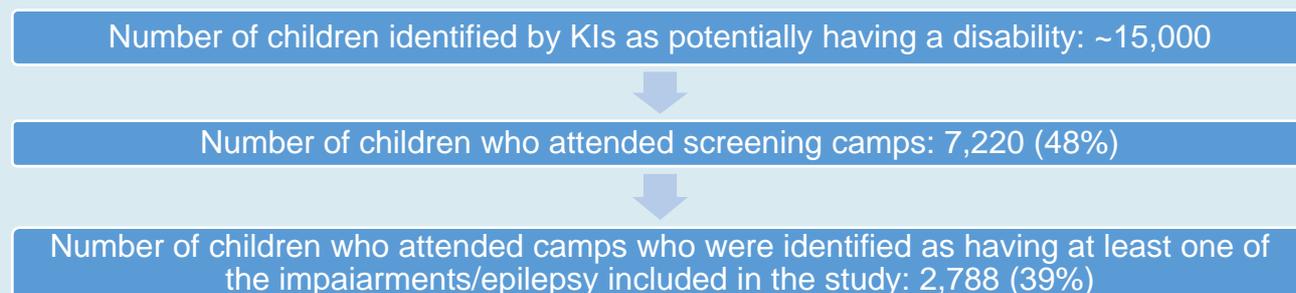


Table 1. Prevalence estimates of impairments/epilepsy in children in study area

Impairment/condition	Number*	Prevalence per 1000 (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 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 from a sensitivity analysis assuming first that the prevalence was $\pm 10\%$ among the non-examined children.

***Per million total population of all ages, not population of children

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 through 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 approximately 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 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.

A full copy of the main project report is available at: <http://disabilitycentre.lshtm.ac.uk>

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