



## Using the Key Informant Method to identify children with disabilities: A working guide



## FUNDER

CBM

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## ACRONYMS

ASHA	Accredited Social Health Activist (India)	KIM	Key Informant Method
CBM	<i>International disability NGO, no long version of name</i>	LHW	Lady Health Worker (Pakistan)
CBR	Community Based Rehabilitation	LSHTM	London School of Hygiene and Tropical Medicine
CI	Confidence Interval	NGO	Non-governmental Organisation
CP	Cerebral Palsy	MOU	Memorandum of Understanding
DPO	Disabled Persons' Organisation	OAE	Oto-Acoustic Emission
ENT	Ear Nose and Throat	PTA	Pure Tone Audiometry
GPS	Global Positioning System	UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
ICED	International Centre for Evidence in Disability	VA	Visual Acuity
KI	Key Informant		

Cover photo: Children waiting at a KIM Assessment Site, Bangladesh

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# 1. Introduction

## 1.1 About this guide

This document is a practical working guide to using the Key Informant Method (KIM) to identify children with disabilities in the community. It is based on the experiences of the International Centre for Evidence in Disability (ICED), with support from CBM, in using this method in a number of different settings including Bangladesh, Pakistan, Malawi and Kenya (final reports from each of these studies are available [here](#)).

KIM is an approach to identifying children with disabilities in the community through trained community volunteers, known as Key Informants (KIs). With the right training and support, KIs have been shown to be able to identify children with disabilities as comprehensively as a population-based survey – providing estimates of prevalence and information on children with potentially unmet needs at up to ten times lower cost than population-based surveys of the same size. KIs can also become long-term disability advocates in their communities and provide an ongoing link between the community and available services. This can be particularly useful if KIs are chosen from cohorts of pre-existing community or volunteer workers who are already supported long term and engaged with service providers. Equally, KI training and methods can be built in to the training of new community worker schemes.

This section (Section 1) of the guide introduces the KIM, [Section 2](#) explains more about how the KIM can be used and the minimum resources you will need, [Section 3](#) provides practical planning information including budgets, recruiting a team and networking amongst stakeholders and communities, [Section 4](#) helps you prepare for and coordinate all aspects of Key Informant Training, [Section 5](#) explains the purpose, protocols and ethical procedures of holding assessment sites to screen children identified by KIs for disabilities, [Section 6](#) provides guidance and templates for analysing, reporting and disseminating results, [Section 7](#) gives advice on overcoming specific challenges you may encounter, [Section 8](#) summarizes and concludes the guide and [Section 9](#) provides links to all the relevant KIM resources on our website that are referenced throughout this document.

The KIM method is still evolving and can be easily adapted depending on the needs of the user. This working guide includes lessons learnt along the way in our use of the KIM in various settings, as well as tips for the best outcomes. There is a linked webpage attached to this guide ([click here for webpage](#)) where you can find examples and adaptable templates of some of the tools and protocols we've developed for KIM along the way. Links to specific resources are provided throughout this guide in the relevant sections. Please note that hyperlinks throughout the document link directly to a download of the specific linked resource. If you would prefer to download the resources via the website, visit <http://disabilitycentre.lshtm.ac.uk/using-key-informant-method-working-guide/>

We strongly encourage users of this guide to get in touch with us and share their own experiences, which we will integrate into future versions of the document. Please feel free to contact us on [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk) with any questions that you have.

## 1.2 Who this guide is for

This guide is for any individual or organisation wishing to identify or quantify the number of children with disabilities in a particular setting. Reasons for this may be primarily to undertake research, programme oriented to facilitate advocacy, or any mixture of the above.

KIM can be used to collect data to learn more about the causes, types, severity and magnitude of impairments, to quantify need for and access to services (including health, rehabilitation, education or vocational training), and to identify gaps and unmet need.

Primary reasons may also be programme orientated, for example to identify children with disabilities and connect them with existing services, or to identify children for enrolment into newly established services.

The data gained from KIM can also be used for advocacy activities. Data on health, rehabilitation and education can be collected, providing robust information for use in advocating adequate measures for inclusion of children with disabilities amongst relevant stakeholders.

Whatever the primary purpose, KIM is useful for simultaneously collecting data on child disability, linking children to services and advocating for inclusion of children with disabilities.

**IMPORTANT:** Minimum resources Use of this guide to conduct a KIM assumes the availability of a minimum set of resources to undertake the study, adherence to ethical protocols regarding working with children, and minimum availability of services to meet the needs of children identified. These are all crucial to the success of the KIM and to the ethics of working with children, and it is imperative that due care is taken to meet the above criteria. This is explored in detail throughout the guide. If you feel you cannot meet any of these criteria, it is strongly advised that you do not conduct a KIM

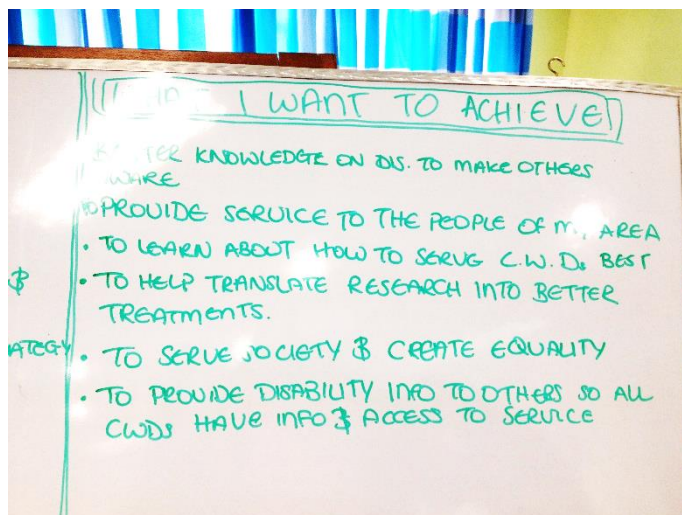


Photo 1: KIM Community Module Training, Bangladesh - KI objectives

Textbox 1: Important point on minimum resources

Figure 1 below describes the KIM.

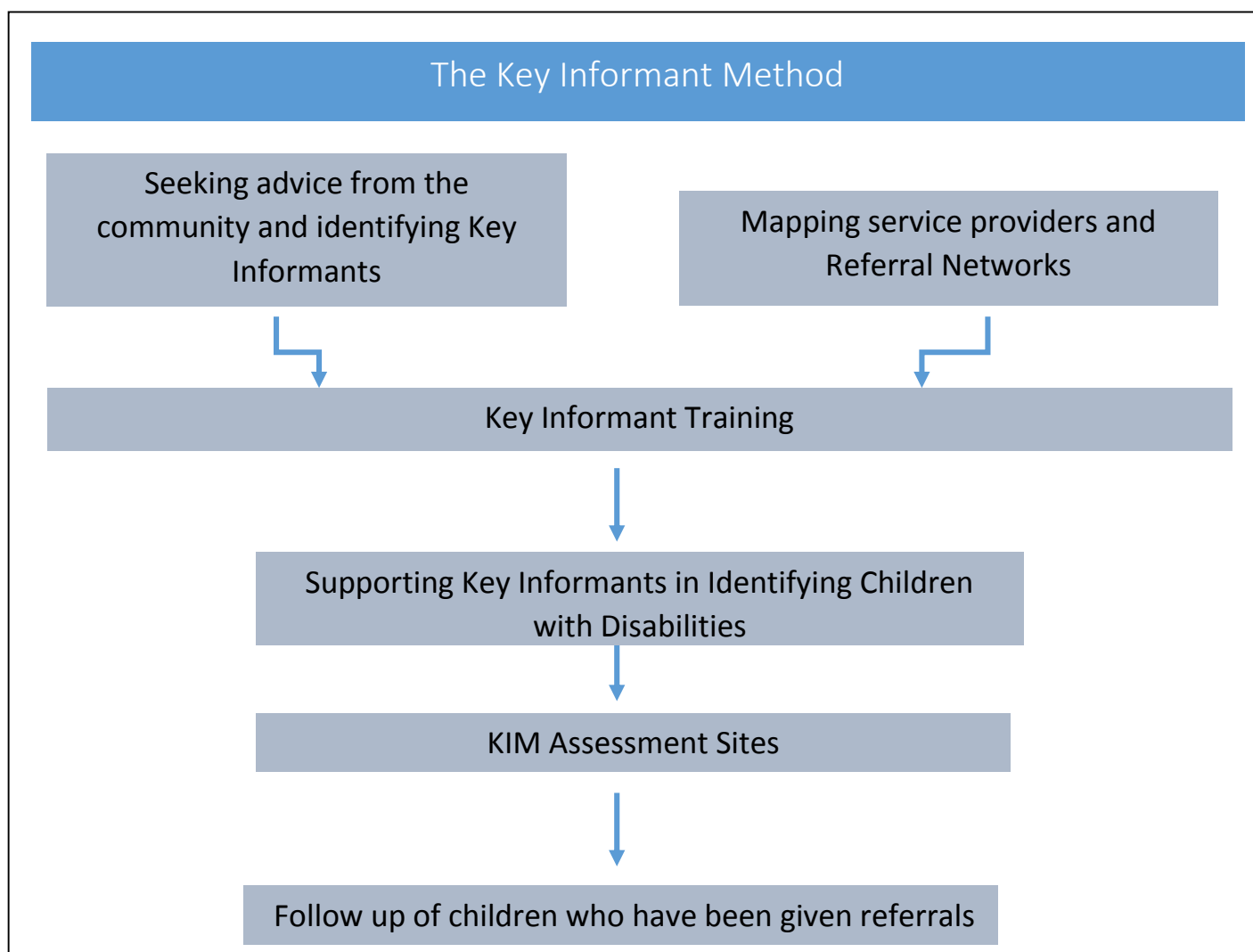


Figure 1: The Key Informant Method

### 1.3 How to use this guide

This document acts as a reference guide based on previous experiences in KIMs undertaken by ICED. It is expected that users use their own judgement to adapt the guidance to their experience, setting and budget. More information on deciding whether a KIM is appropriate in meeting your needs is given in section 3.1 (“Deciding to conduct a KIM”).

We suggest that you first read this guide through to the end before deciding whether or not to embark on a KIM, to ensure that it is the most appropriate method to meet your needs. It is essential to follow all key steps of the method, and to ensure that you have adequate resources available to complete the activities, including providing appropriate follow up support for children with disabilities.

Whilst we cannot provide step by step assistance in carrying out a KIM, we are happy to hear from those with specific queries or who want to share their own experience with us. If you have any questions or want to get in touch, please contact [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk)

#### KEY POINTS FROM THIS SECTION:

- This is a practical guide to using KIM to identify children with disabilities based on experiences of ICED and CBM
- The intended audience is any individual or organisation wishing to identify or quantify the number of children with disabilities in a particular setting
- Reasons for doing a KIM may be research, advocacy or programme orientated or to identify children for enrolment into new or previously established services
- Read the guide through to the end before deciding whether or not a KIM is the most appropriate method to meet your needs and whether you have the resources to complete all activities, including providing appropriate follow up, and to meet all ethical considerations when working with children

*Textbox 2: Key Points from Section 1*

## 2. The Key Informant Method (KIM)

This section explains what the KIM is and how it has, and can be, used to identify children with disabilities. It also describes the minimum resources you will need to conduct a KIM and essential ethical considerations that must be met when working with children in a KIM.

### 2.1 Defining the KIM

The term Key Informant (KI) has been used by a number of programmatic and research organisations to refer to community based volunteers who are recruited based on their social knowledge and standing. A strong social standing allows KIs to help identify targeted groups within their communities or understand and relay community perspectives. KIs have been recruited by different organisations to assist in programme implementation, evaluation, and identification of specific groups such as people living with HIV/AIDS [1-3].

Specifically, the Key Informant Method (KIM) has been used and validated by a number of organisations, including ICED, to estimate the prevalence of specific impairments and health conditions in children.



In the KIM, KIs are trained and supported to identify children with specific moderate or severe impairments or health conditions in their local communities. These children are then assessed for disability by a team of health and rehabilitative professionals using objective criteria at a designated KIM assessment site. Children with unmet health, rehabilitative, educational, vocational or other needs can then be referred to appropriate services or included in new or ongoing programmes, with available services mapped in detail prior to any data collection. Further information can also be collected for research purposes on the children’s lives and access to services.

KIs are trained to identify impairment visually and through the use of short question sets. Measures of activity limitation and participation restriction are not directly included in KI training, and should be included at KIM assessment sites.

So far, the KIM has been used by ICED to identify children with targeted *moderate* or *severe* impairments only, based on international thresholds and criteria (See Section 5.4 “Screening and Definitions” for more on thresholds and how these are established). Further potential developments for KIM include validating it for the identification of children with mild impairments as well. Section 7.6 on “Inclusion of mild impairments” has more information on the pros and cons of expanding KIM to include identification of mild impairments.

Table 1 provides a timeline of KIM development in projects coordinated by ICED.

For a glossary of terms, including definitions of “disability” and “child” used in this guide, please refer to Annex 1.

## 2.2 How the KIM can be used

### 2.2.1 Using KIM to build evidence on the prevalence, magnitude and impact of targeted impairments and health conditions in children

Limited data exists globally on the magnitude of child disability, and country estimates range from 0.4% to 48.0% of children[4]. This is due at least in part to the use of non-comparable methods and definitions of childhood disability. This lack of data overall is due to the high cost of completing population-based surveys of childhood disability [5, 6].



Photo 2: A mother waits for her child to be assessed, Bangladesh

Table 1: KIM Development by ICED				
Year	Study Country(ies)	Impairments/ health conditions included	Key Findings	Study Citation
2006	Bangladesh	Severe Visual Impairment (SVI) and blindness	Children with avoidable severe visual impairment (SVI) or blindness 30-40% more likely to be identified by KIs than through CBR or special education centres	Muhit, M.A., et al., <i>The Key Informant Method: A Novel Means of Ascertaining Blind Children in Bangladesh</i> . British journal of ophthalmology, 2007. 91(8): p. 995.
2008-2012	Bangladesh and Pakistan	Moderate/Severe Visual Impairment, hearing impairment, physical impairment and epilepsy	9.0/1000 prevalence of targeted impairments/health conditions in children in Bangladesh  KIM was determined not to have been successfully implemented in Pakistan, due to inconsistencies in the data and security concerns limiting support the team could provide	Murthy, GVS, et al. <i>Assessing the prevalence of sensory and motor impairments in childhood in Bangladesh using key informants</i> Archives of disease in childhood, 2014. 99 (12) p. 1103-1108.  Link to study summary report <a href="#">here</a> .
2011-2012	Bangladesh	Cerebral Palsy	14 parent groups (153 families) established to train caregivers in supporting their children with Cerebral Palsy and a Parent Training Manual and Community of Practice developed through operational research	Link to manual <a href="#">here</a> .
2013	Malawi	As above, plus intellectual disabilities	17.3/1000 prevalence of targeted impairments/health conditions in children	ICED, <i>The Malawi Key Informant Child Disability Project Report</i> LSHTM 2014  Link to study report <a href="#">here</a> .
2013	Kenya	As above	7.5/1000 prevalence of targeted impairments/health conditions in children	ICED, <i>Childhood Disability and Malnutrition in Kenya Project Report</i> LSHTM 2014  Link to study report <a href="#">here</a> .

Table 1: KIM Development by ICED

Low prevalence of childhood disability means that household surveys of child disability require very large sample sizes to be able to make meaningful interpretation from the data, often at considerable cost. Additionally, children with disabilities may be hidden from view due to stigma and perceived shame, meaning that survey teams do not see and therefore do not register all disabled children. KIs are much more likely to be able to identify all children with disabilities living in their community, given that they are trusted, long term members of the same population.

KIM has been shown to cost ten times less than a population-based survey covering the same sized population[7]. This low cost compared to survey methods and the ability of KIs to identify *all* children in their communities makes it a good option for those wishing to build evidence on child disability in a comprehensive, comparable and cost-effective way.

### 2.2.2 Using KIM to plan and support health and rehabilitative services

The lack of data on the prevalence of childhood disability and specific impairments is identified in the 2011 World Report on Disability as a major barrier in designing effective health systems[8]. These data are of urgent need in low resourced settings especially, to plan effective primary, preventative and rehabilitative services for children with disabilities.

Identifying children with disabilities via a KIM provides information not just on need but also on current coverage of services and specific gaps. See Textbox 3 for an example from KIM Bangladesh.

#### Example: Using KIM to plan and support health and rehabilitative services

The KIM in Bangladesh established that Cerebral Palsy was the lead cause of childhood disability in the country but that services were scarce. This led to the establishment of an effective parent-led training project on caring for children with cerebral palsy, and beyond this a manual and community of practice, expanding usage of the method globally.

Full resources related to the CP Parent Training Project are available [here](#)



Photo 3: Parent Group Training in Bangladesh

Textbox 3: Example on planning and supporting services

### 2.2.3 Using KIM to inform CBR/ inclusive community development programmes

KIM can be an effective way to identify children with disabilities for enrolment in a specific programme or service, such as Community Based Rehabilitation (CBR) or other inclusive development programmes.

Moreover, experience has shown that many children with disabilities are unable to access existing services, for a variety of reasons (See Section 7 on “Potential challenges” – click [here](#)). KIM can assist in identifying children in the community and supporting service access. Children identified by KIs can then be followed up either at home or at a KIM Site.

Note that even if using KIM to identify participants for inclusion in a particular project, you can still use it as an opportunity to collect other data on child disability that is useful in the service setting.

As mentioned previously, the KI role can be developed as part of a wider community-based role, to create a long-term link between the community and available services. See Textbox 4 for an example from Bangladesh.



Photo 4: KI Community re-training

#### Example: KIs as long term advocates:

Based on their feedback that they wished to remain active in disability inclusion after the project was over, 300 of the original 1500 KIs in Bangladesh were provided with further knowledge, information and capacity training to link communities up with referral services and further promote disability awareness and inclusion.

Textbox 4: Example of KIs as long term advocates

### 2.2.4 Using KIM to identify other groups

Whilst KIM has been used at ICED to identify children with specific impairments/ health conditions only, the method can be adapted to identify other target groups including adults with disabilities, or children or adults with one specific health condition (e.g. Epilepsy). Bear in mind however that targeting a single health condition may be difficult, especially if you are conducting the KIM in a resource-poor setting with low service access. You will probably find that caregivers of children with other unmet health needs also request assessment, and it is worth considering broadening your list of targeted health conditions and/or impairments to identify and support a greater number of children with unmet needs.

## 2.3 How BIG should a KIM be?

KIM was originally designed with the aim of identifying children with disabilities at the district level – i.e. the administrative level (however named) that is equivalent to a population of up to approximately 200,000 (total all-age population). A KIM can be as large or as small as your objectives require, but there can be advantages from district as opposed to smaller coverage. The resources that you need to conduct a KIM in a districts of 200,000– staff salaries, training, equipment, vehicles etc. – will not be much more than the cost of conducting the KIM in an area half the size (e.g. population 100,000).

You need to decide the best, and most feasible size dependent on the resources available to you. In Bangladesh, three districts of 200,000 each were covered (600,000 in total), whilst in KIM Kenya the total estimated population was less than 100,000 [9]. Equally, KIM has not yet been tested at a national level. You should always carefully plan your available resources before determining the size of KIM that is feasible (see below).

## 2.4 What resources do you need to carry out a KIM?

Below is a list of the *minimum* resources needed to carry out a KIM. As previously mentioned it is advised that you read this guide through to the end first. You can then determine a specific, carefully budgeted work-plan based on your own decisions regarding the various available options within the methodology, before beginning moving forward on conducting a KIM.

Minimum resources to be identified and (where applicable) budgeted in your local setting:

- ✓ Full time committed and dedicated project manager to oversee all activities and manage field team and KIs
- ✓ Competent team of salaried field staff to act as KI coordinators (minimum 1 coordinator per approximately 100 KIs), to train KIs, support project logistics and supervise assessment sites and follow up
- ✓ Cohort of enthusiastic and motivated community-based Key Informants (minimum 1 KI per approximately 200 children in the community)
- ✓ Clinically trained personnel to undertake clinical assessment of impairments in children identified at assessment sites (see Textbox 5, next page)
- ✓ Support from child disability and local authority stakeholders
- ✓ Access to and detailed awareness of appropriate referral services (service mapping)

- ✓ Adequate funding to cover:
  - ✓ Salaries of field staff
  - ✓ Per diems for clinical staff involved in KIM site screening
  - ✓ Per diems for clinical specialists to assist in training clinical staff
  - ✓ KI incentives and training costs
  - ✓ KIM Assessment site venues
  - ✓ Basic medicines and any clinical assessment equipment needed<sup>1</sup>
  - ✓ Transportation and fuel for field teams
  - ✓ Mobile phone costs for field staff (these can be significant!)
  - ✓ If distances are significant, transport costs for caregivers to attend assessments offered at KIM sites
  - ✓ Printing of all forms and resources/ purchasing and maintaining electronic data entry platforms
  - ✓ Storage of all forms and resources
  - ✓ Data entry staff and equipment
  - ✓ Competent data analyst
  - ✓ Dissemination of results (including dissemination workshop session and printing of reports)



*Photo 5: KIM Kenya Field Team*



*Photo 6: KIM Bangladesh medicines for assessment sites*

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<sup>1</sup> A full list of all clinical equipment needed is included in the clinical protocols document, available [here](#)

### Example: Previous KIM Team Sizes

To give you an idea of team sizes, the teams for KIM Bangladesh and KIM Kenya are provided below.

KIM Bangladesh (child population 247,000 covered)	KIM Malawi (child population 338,235 covered)
Project Manager – Full Time	Project Manager – Full Time
Key Informant Coordinators (x4) – Full Time	Project Coordinator – Full Time
Paediatrician (x2) – Consultancy for KIM site Days	Social/Rehab. worker – Full Time
Ophthalmologist – Consultancy for KIM site Days	Rehab. technician – Consultancy for KIM site days
ENT doctor – Consultancy for KIM site Days	Nurse (x2) - Consultancy for KIM site days
Audiometrician – Consultancy for KIM site Days	Orthopaedic clinical officer - Consultancy for KIM site days
Physiotherapist – Consultancy for KIM site Days	Ophthalmic clinical officer - Consultancy for KIM site days
Community disability worker – Consultancy for KIM site Days	ENT clinical officer - Consultancy for KIM site days
Counsellor – Consultancy for KIM site Days	Audiologist - Consultancy for KIM site days
1500 x volunteer KIs	500 x volunteer KIs

*Textbox 5: Example of previous KIM team sizes*

## 2.5 Ethical considerations and minimums of service availability

Local ethical clearance must be sought from all relevant research or programme bodies, and country and/or district authorities. If you do not know the ethical clearance procedures in your country, contact the Ministry of Public Health (or similar) in the first instance to seek advice on which ethics committees you need to apply to for approval to conduct public health research or programmes.

You must follow all appropriate ethics mechanisms. This is to ensure complete protection of all children identified and to guarantee adherence to local, national and international ethical protocols.

Informed consent should always be taken from an adult caregiver of any child included in the study, and you should also take assent from the child his or her self if s/he is old enough to do so and able to communicate independently or with assistance.

Children should never be assessed without the caregiver's presence.

Always take specific written or thumb print (if illiterate) consent for any photos taken of the children and their caregivers throughout the process, especially if intending to use these in future reports or other outputs.

It is not ethical to identify children with significant unmet health or rehabilitative needs without providing onward referral pathways to the best of your ability. See Section 3.5 on "Mapping service providers and referral networks" for more. If no services are available within the project vicinity, consider whether the method is acceptable.

Textbox 6 provides an example ethical protocol.

### Example of Ethical Protocols:

Informed consent must be taken BEFORE any screening or examinations take place. Child-friendly information sheets – with a focus on pictorial information in a simple format that children can easily understand – should be included. A sample children’s information sheet ([click here](#)) and children’s consent form ([click here](#)) are available.

Introduce yourself and ask both the participant and their caregiver’s name. The caregiver accompanying the child MUST be aged 18 or above. If not, explain that you need an adult caregiver to accompany the child and ask them to return with one. If one adult caregiver is responsible for several children, they must be present throughout each child’s interviews.

If the caregiver is 18 or above, explain about the study using a pre-prepared information sheet (link to example information sheet for parents – [click here](#)) as a guide. You can paraphrase but you must cover all the following areas:

- Study purpose
- What is involved in the study
- Participation is voluntary
- Confidentiality
- Ask if they have any questions

If the caregiver is willing for their child to participate, obtain their name and signature on the consent form. If they cannot write, ask them for a thumbprint using the inepad.

If the child is old enough to understand, ask the child directly whether they have any questions, and request assent from the child (via signature or thumbprint) before beginning.

For children less than 8 years the child’s caregiver should answer the questions on their behalf

For children 8-17 the child should be interviewed directly where possible, but a caregiver must be present at all times.

For older children unable to communicate independently, the child’s caregiver should answer the questions on the child’s behalf and this should be marked on the form.

All screening and assessment should stop immediately if the child is unwilling to continue

Obtain the signature of a witness to show the caregiver has willingly agreed to take part in the study. The witness must not be a member of the survey team, but can be any other individual aged 18 or over.

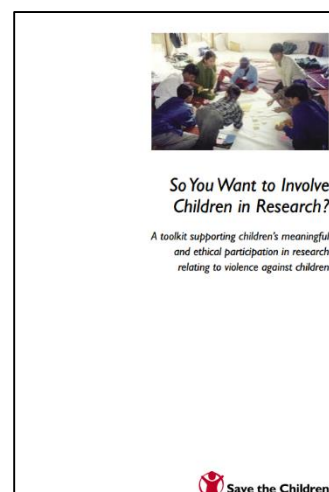
*Textbox 6: Example of Ethical Protocol*



### **IMPORTANT:** Child Safe-guarding

It is mandatory that all field staff that have not previously undertaken child safeguarding training do so prior to field work commencing. Several courses are available online for a small fee. It may be worth considering paying for a consultant to deliver the training to the organisation as a whole so as to ensure that all staff abide by a child protection-centred code of conduct.

“So You Want to Involve Children in Research?” is an excellent resource by Save the Children on methods and tools to support meaningful and ethical participation of children in research related to violence. Many of the tools and methods are applicable generally to research with children. [Link to the resource here.](#)



*Textbox 7: Child Safe Guarding*

### **KEY POINTS FROM THIS SECTION:**

- KIM has been by ICED as a methodology to identify children with specific moderate and severe impairments or health conditions (Section 2.1)
- KIM can be used to build evidence on child disability prevalence, magnitude and impact (Section 2.2.1)
- KIM can also be used to plan and support services, or to inform CBR or other inclusive community development programmes (Section 2.2.2 and 2.2.3)
- Scale of study can be as big or small as resources allow, but was originally designed for district level - administrative level equivalent to approximately 200,000 all age population (Section 2.3)
- KIM requires a minimum of resources to be conducted successfully and should not be attempted if these resources are not available (Section 2.4)
- Obtaining relevant ethical clearance and adhering to ethical protocols at local, national and international levels are essential to ensure protection of children identified in the study (Section 2.5)
- If not previously undertaken, arrange for all team members involved in the project to undertake a child safeguarding training course either through hiring a consultant to come and train the team or online. (Section 2.5)

*Textbox 8: Key Points from Section 2*

## 3. Planning for a KIM

The section below outlines important steps to cover in planning a KIM, including how to decide whether a KIM is appropriate and feasible, recruiting and training a salaried field team, establishing an advisory committee, mapping referral services and identifying Key Informants.

**“GOOD investment at the beginning and well trained KIs are key to a successful KIM” – KIM Coordinator, Bangladesh**

### 3.1 Deciding to conduct a KIM

Before you begin, you need to determine the purpose of undertaking a KIM, and the ways in which you will go about (and fund) it. It may be useful to hold a planning meeting with other members of your organisation and other stakeholders in child disability.

Key questions for discussion during a planning meeting would be:

**WHAT is the purpose of conducting this KIM? Is the KIM right for my purpose?** Section 2.2 “How the KIM can be used” will help you with this.

**WHAT do I want to measure in this KIM?** You need to decide which impairments and/or health conditions you want to target in KI identification. Again, the information in Section 2.2 “How the KIM can be used” can help with this.

**WHAT human resources are available to run this KIM? Are there experienced clinicians in the region who will be willing to work on a consultancy basis assessing identified children at KIM Sites?** See Section 5.2 on KIM Site Personnel Requirements to assess the human resources you would need.

**HOW big is the KIM going to be? What geographical range will it cover?** Use Section 2.3 “How BIG should a KIM be” to decide.

**HOW big a team (paid and KIs) will I need?** You can base this on the information in Section 2.4 “What resources do you need to carry out a KIM” on how many coordinators you need per KI and how many KIs you need per 200 child population

**WHO is going to fund this KIM? How much money do I need?** Again, section 2.4 and guidance throughout this document and from ICED should help.

**WHO is going to coordinate this KIM? What team do I need to recruit?** Use the information provided throughout this guide to decide how you would run the KIM.

**WHO is going to be responsible for analysing, writing up and disseminating the data collected? Is this something I have the capacity to do, or do I need to recruit someone with analytic and writing skills to complete this?** (see Section 6 “KIM Results and dissemination”).

ICED is available to assist on some of these decisions, and encourage prospective users of the KIM to contact us on [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk) for advice.

### 3.2 Establishing an advisory group

Once you have determined that you would like to conduct a KIM and have the necessary resources to do so, you should establish a local advisory group before beginning any further activities. This provides the following benefits:

- ✓ Context-relevant input into study design and protocol
- ✓ Technical advice and knowledge about support for and management of child disability in the study area
- ✓ Assistance in networking with different agencies providing services for children with disabilities
- ✓ Ownership and collaboration from key stakeholders from inception of project, leading to better integration of findings into policy and services

Members of the advisory group should be appropriate stakeholders in child disability your setting, but should generally include:

Policy Makers	You should seek out representatives from government ministries with responsibilities for child disability and especially representatives from ministries such as health and/or education that may have limited awareness of disability inclusive policies.
Service Providers	These should include representatives of services related to education, primary or rehabilitative health and vocational services
Disabled People's Organisations (DPOs)	It is very important to include representatives from DPOs to ensure that the proposed project design and protocol is relevant and acceptable to people with disabilities in the country
NGOs	These should be both NGOs working on disability and "mainstream" NGOs who may not currently be focused on disability but work with children, in education or in health

Ideally, an advisory group will include 10-15 representatives of the above organisations and stakeholder groups, and an even distribution of men and women, as well as people with disabilities.



*Photo 5: Vision Screening in KIM Pakistan*

As a minimum, you should aim to hold an advisory group meeting at each of the following key project time points:

- 1) Planning – to gain insight and advice on a pilot protocol, including service mapping and networking
- 2) Post Pilot – to gain feedback and advice on worked well and did not work well during the pilot test, and what can be improved in the final protocol
- 3) Post data-collection – to share findings and request assistance in 1) supporting identified children long term 2) disseminating results

### 3.3 Attaining Necessary Permissions

You should always make sure to get all the necessary permissions to undertake a community project including national or district level official permission and permission from community leaders. Carry written approval from each level of authority with you when meeting with other stakeholders.

### 3.4 Recruiting and training a field team

Key to the success of a KIM is a dedicated, full time field team. You will need one full time project manager and a number of full time KI Coordinators (the exact number will depend on the size of the KIM). Responsibilities and terms of reference for these roles are explained below.

If your field team are not committed and well informed on the protocols and rationale of the KIM, the potential for success will decrease. A successful KIM requires strong coordination and leadership to make sure that KIs are well trained, supported and motivated in identifying children with disabilities.

First identify a dedicated project manager. The key responsibilities of this role are:

- ✓ Overall management and coordination of project activities
- ✓ Recruitment, management and training of Key Informant coordinators
- ✓ Supporting Key Informant Coordinators in organising KI Training sessions
- ✓ Supporting Key Informant Coordinators in coordinating KI identification
- ✓ Recruitment and coordination of clinical team members for KIM Sites
- ✓ Coordination of field schedules and logistics of KIM Sites
- ✓ Management of project budget and reporting to donors
- ✓ Management of collected data and referrals if applicable
- ✓ Responsibility for data storage
- ✓ Coordination of data entry and analysis
- ✓ Writing reports if applicable

Once you have recruited a competent project manager, it is important to recruit field staff to act as Key Informant Coordinators. Key Informant Coordinators should be dedicated and salaried project staff, ideally with previous disability and/or health experience and experience working with children. For best results, these staff should be based in or near the study area, and there should be no less than one KI Coordinator per 100 Key Informants (see Textbox 9 for an example of the KI Coordinator cohort from Malawi).

**Example: KI Coordinators:**

In Malawi, District Environmental Health Officers were engaged as KIM Area Coordinators. In Bangladesh, this role was undertaken by “Community Mobilisers” already working as field workers with the Bangladeshi NGO Child Sight Foundation (CSF), the partners on the study.

*Textbox 9: Example from KI Malawi and Bangladesh*

Key Informant Coordinators should work directly with the project manager and are usually responsible for:

- ✓ Liaising with community stakeholders
- ✓ Mapping local referral services
- ✓ Identifying Key Informants
- ✓ Training Key Informants
- ✓ Supporting and retaining Key Informants via phone and in person
- ✓ Cross checking Key Informant lists for duplications and children requiring home visits
- ✓ Organising and overseeing KIM Sites
- ✓ Recording attendance and referrals

### 3.5 KI Coordinator Training

Training of KI Coordinators should be undertaken by the Project Manager, ideally with the assistance of disability specialists and/or DPO representatives.

The exact content for KI Coordinator Training will depend on your reasons for conducting a KIM and your specific resources and setting. However, key areas to cover in a three or four day KI training (depending on level of prior experience and knowledge of disability), with rough time allocation for each section, is given below.

The below timetable assumes some prior knowledge of disability amongst KI Coordinators – if this is not the case, spend the whole of the first day on items 1, 2 and 3. Note that further training for KI Coordinators, including more practice filling in forms and practicing any screening activities they will undertake in KIM Assessment Sites is usually undertaken during the training for the whole field team including clinical team members and (if you have them) fieldworkers. This is covered in Section 5.2 “Training Requirements for Field Staff”.

If you do not intend to hold a separate training for field staff then make sure to spend longer training the KI Coordinators on data collection, KIM Site procedures and screening for impairments.



*Photo 6: KI Coordinators registering caregivers and their children, Pakistan*

### 3.5.1 Example KI Coordinator Training Timetable

#### Day 1:

##### **9:00- 9:30:**

##### 1) Icebreakers and Introductions

The KI Coordinators will be central to the success of your KIM, so spend some time getting to know them and letting them get to know one another. Ask them to introduce one another, for example, and to tell you two or three interesting facts about each another.

##### **9:30-10:30**

##### 2) Who you are and why you are undertaking a KIM

Provide details about your organisation, its background and why they have been recruited. Specifically, give an overview of:

- Study aims and objectives
- Study methods
- KI Coordinator roles and responsibilities
- KI Coordinator support

##### **11:00-13:00**

##### 3) Key concepts about child disability including breaking down stigmas

Use participatory and questioning methods to ask KIs what they understand about disability – what causes it, what impact it has, and what rights children with disabilities have. A great resource for this is UNICEF’s “It’s about Ability” explanatory guide to the UNCRPD, available from: [www.unicef.org/publications](http://www.unicef.org/publications).

If possible, see if you can identify a representative from a local DPO in assisting you in this section from a local perspective.

Another very good training resource is the Game of Life, available at [www.worldvision.org.uk/travellingtogether](http://www.worldvision.org.uk/travellingtogether). This game allows members of the group to discuss the barriers and stigmas relating to disability in the community, and should encourage awareness about disability rights in a simple, informative and relaxed way.

Once you feel that KI Coordinators have a general acceptance and understanding of the social model and the rights of children with disabilities, use/adapt the KI Coordinator Training PowerPoint to inform KI Coordinators about specific impairments and health conditions. If no projector is available, print out the slides to hand out. Always use your preferred style of presenting, making sure that the key messages come across. KI

Coordinators need to be able to identify specific impairments and be comfortable in doing so, so that they can then train KIs confidently. Link to download KI Coordinator Training PowerPoint [here](#).

#### **14:00-15:00**

##### 4) KIM research project and processes

Use this session to go through the KIM methodology in detail with KI Coordinators. Be specific about the various stages of the project as laid out in this guide and based on your own work plan for the KIM. Go through the specific details of their roles and responsibilities within the overall project, and allow time for questions.

#### **15:00-17:00**

##### 5) Their role as KI Coordinators

This session will be the first introduction KI Coordinators have had to their role in the KIM, so adequate time should be spent in explaining the various activities that they will be responsible for. Time should also be allocated to practicing these roles (see Day 2).

You should introduce to them:

- ✓ The format of the KI training sessions that they will be running. Previous KIMs have found that KI training works well using laminated flip-charts or PowerPoint slides that provide visual cues on identifying specific targeted impairments and health conditions in children. Descriptions and details are provided for KI Coordinators on the back of each page on how to determine whether a child should be referred to the KIM Site. There is a link to download the Malawi KI Training Flipchart [here](#) and Bangladesh KI Training Flipchart [here](#). Use or adapt these to your own needs.
- ✓ Written KI Material that they will be responsible for distributing to KIs. The link to download the “Disability Awareness and Information for KIs” sheet, which gives KIs information about raising awareness in the community and simple information on identifying targeted impairments is available [here](#).
- ✓ An overview of the timetable for KI training sessions (see Section 4.2 “Key Informant Training Content” for more details on this)
- ✓ An overview about supporting KIs in identification of children with disabilities and counselling parents on attending KIM sites (see Section 4.5 “Supporting Key Informants in Identifying Children with Disabilities” for more)
- ✓ Their responsibilities assisting clinical screening modules of forms (see 5.2 on “Screening and Definitions” for more)
- ✓ Their responsibilities filling in non-clinical modules of forms (see section 5.4 “Collecting Other Data” for more)



## Day 2:

### 9:30-12:30

#### 6) Recap on child disability

Spend the first session of Day 2 recapping the key messages about identification of children with specific impairments or health conditions in the community. Go through the KI Coordinator Training PowerPoint a second time but this time ask the KI Coordinators to take turns presenting the information. Give them time to ask questions and clarify any doubts. If possible, ask a clinician such as paediatrician to join you to answer any clinical questions KI Coordinators may have.

### 13:30-17:00

#### 7) KI Training

This entire afternoon should be spent practicing KI Training. Use Section 4 to explain the process of KI training including preparations, recording KI details, the KI training timetable and content. Go through the KI flipchart in detail and let the KI Coordinators take turns practising in front of one another. Ask the KI Coordinators to pretend to be trainees and to ask the presenter questions that they think KIs may ask them in training.

## Day 3:

### 9:30 – 11:30

#### 8) Supporting Key Informants in Identifying Children with Disabilities

Regular communication and provision of support and feedback to KIs once they have been trained is really key to the success of a KIM. Use this session to also discuss KI Coordinators visiting listed KI children in advance of KIM sites if you have decided to do this and to introduce to them forms such as KI Profile Forms and KI List forms (see Section 4.3 “Key Informant Training Materials” for more).

### 11:30 – 13:30

#### 9) KIM Forms

Print and distribute copies of all the data entry forms that will be filled in at the KIM Sites by the KI Coordinators and other members of staff. These can be practiced in detail at a later date when you run the Full Field Team Training (See Section 5.2 “Training Requirements for Field Staff” for more). In this session, spend time introducing the KI Coordinators to the types of data that will be collected at the KIM Sites and briefly introducing the screening and non-clinical modules that they will assist in completing. Note that if planning to use mobile

devices for electronic data collection, spend time first using paper copies and go through step by step before introducing tablets. This will give the KI coordinators a better overall understanding of the data to be collected in each module, including the data that will be collected by other members of the field team than themselves (e.g. clinical data).

#### **14:30 – 17:30**

##### 10) KIM Site Logistics Procedures

This will also be covered further in the Full Field Team Training, but not in as much detail. Explain carefully each of the following processes that KI Coordinators will either be responsible or involved in, using the relevant sections of this Guide.

- General organisation and registration (Section 5.3 “Logistics of KIM Site organisation”)
- Ethics and Informed Consent (Section 2.5 “Ethical considerations and minimums of service availability”)
- Referral process & procedures (Section 5.7 “Referral Procedures and KIM Site exit procedures)

#### Day 4:

#### **09:30 – 12:30**

##### 11) Final shared discussion time for any questions or issues arising

Hold a wrap-up session to go over the activities and responsibilities covered in the training, with plenty of time for questions and recapping any areas in which there is confusion.

### 3.6 Mapping service providers and Referral Networks

It is very important to research and map out onward referral pathways available for all children with unmet needs identified in the KIM. This process should be completed prior to identification and training of KIs and is important both ethically and to establish a network of providers of services in health, rehabilitation or education.

The programme manager and KI coordinators should work with key stakeholders, including members of the project’s advisory group, to establish which service providers are operating in the area the KIM will be conducted in. If you are conducting the KIM away from large urban areas, it is likely that complex health or rehabilitative services (for example surgical procedures or fitting of worn assistive devices) are only available at some distance. It is therefore important to map the distance to each service provider from the areas you will be

working in and to assess the feasibility of participants from the study area accessing these services (considering time and transport costs).

Where possible, providers of the following services should be mapped:

Health

General Paediatric Care  
Vaccination  
Ophthalmology  
Ear, Nose and Throat (ENT) and Audiology  
Orthopaedics  
Psychiatrist

Rehabilitation

Physiotherapy  
Orthotics  
Community Based Rehabilitation  
Inclusive or specialist education  
Vocational Training

Other

This process also allows you to identify key gaps in service provision that need to be addressed through appropriate channels. This may be of particular importance if your aim in conducting the KIM is programmatic or needs-based.

**IMPORTANT: Tie in with local service provision** Make sure to tie in to local and available service provision and do not establish a dual or independent service as this will not be sustainable once the KIM is finished. Many impairments or health conditions in children require long term care and reassessment, which can only be ensured through established service providers.

*Textbox 10: Important information on local service provision*

Experience from previous KIMs and other studies has shown that many barriers to referral service uptake exist, even when caregivers are aware of the potential gain.

Most common barriers include:

- Cost or perceived cost of service
- Misinformation/misunderstanding about service
- Distance, meaning high transport costs and/or too many days away from home for the parent and child

Through referral mapping you can clarify exact costs and information regarding services that you will refer children to, to minimise these potential barriers. Barriers related to transport costs and distance can also be addressed through working with service providers to discuss community transport options – for example, would the service provider consider/are there NGOs or other third parties who will support funding a vehicle to transport children to services and back?

It is really important to meet directly with all service providers that you intend to refer children to and explain who you are and your intentions. You should gather accurate information on:

- The exact services they provide
- The cost of these services
- Any existing subsidies for services (e.g. with beneficiary card/ through a health insurance scheme)
- The quality of services
- The provider's capacity to assist in the transportation or other costs associated with service provision



*Photo 7: Assistive Devices donated by a local NGO in KIM Bangladesh*

You should also be clear about the estimated numbers of children you expect to refer to the service provider and rough timelines when you expect this to happen, so that the service provider is aware and can be prepared for a potential influx of new service users. Not only does this assist the service provider's planning, but has the potential to ensure better quality care amongst children referred than if they were to arrive unexpectedly.

Once you have decided the geographical distance that you will cover, you can use findings from previous KIMs or other studies in your area to estimate roughly how many children you are likely to identify and roughly how many will need specific services.

For example, KIM Bangladesh estimated the prevalence per million general population (all ages) of specific physical impairments, visual impairments, hearing impairments and epilepsy— see Table 2 next page.

Using this data, or data from the KIM Malawi or Kenya, you can estimate the proportion of children you would expect to identify in a population the size you are covering, and can share this information with service providers to assist their planning. The table also includes the costs of services provided in the study, with costs then extrapolated to the national level. In instances where several referral options were possible (e.g. an assistive device or surgery), the figures account for the proportion of each referral type offered amongst the cohort. This information can be extremely useful for service and budget planning.

Consider suggesting a formal Memorandum of Understanding (MoU) with core service providers to ensure that there are no miscommunications when participants begin arriving

based on referrals through the KIM. If the services are generally chargeable, consider lobbying for these to be covered by the service provider or others, e.g. stakeholders related to the Advisory Group. A MoU or formal agreement encourages a sustainable link between services and participants, many of whom may have long-term service requirements.

Table 2: Estimating the prevalence of specific impairments and the costs of service provision from KIM Bangladesh

Impairment/Health Condition <sup>2</sup>	n (study)	Prevalence/ Million general popn	Estimated National Magnitude	Average Cost per Child (£)	Cost/Mil Popn (£)	National Cost (£)
Physical						
- Cerebral Palsy						
CP (no other presentations)	711	1138	176,413	95	108,124	16,759,276
CP and Epilepsy	130	208	32,256	167	34,753	5,386,689
CP and severe visual	23	37	5,707	159	5,854	907,375
CP and hearing	53	85	13,150	140	11,878	1,841,052
CP plus multiple Impairments	36	58	8,932	165	9,509	1,473,834
- Club foot	144	231	35,729	88	20,285	3,144,179
- Cleft Lip/Palate	107	171	26,549	156	26,720	4,141,622
- Hydrocephalus	39	62	9,677	107	6,680	1,035,405
- Polio	28	45	6,947	33	1,479	229,263
- Other Physical	273	437	67,737	95.8	41,866	6,489,186
Epilepsy	202	323	50,120	72	23,282	3,608,660
Visual	121	194	30,023	64	12,396	1,921,442
Hearing	397	636	98,504	111	70,541	10,933,911
Multiple (not CP)	70	112	17,368	165	18,489	2,865,788
<b>TOTAL</b>	<b>2334</b>	<b>3736</b>	<b>579,112</b>		<b>391,856</b>	<b>60,737,680</b>

Table 2: Estimating the prevalence in KIM Bangladesh

You may also want to think about building referrals into your data collection so as to formally assess further down the line what services children identified in KIM accessed and what their experiences of the services were. With a clear idea of the costs of each service, you can also then use this information to analyse the resources needed to fully meet the needs of children with disabilities at a district or national level. If you choose to do this, you can organise this by giving each child a stamped referral slip with an individual ID number and asking service providers to fill in a simple database on attendance by ID.

Textbox 11 provides important information about why you should not pay directly for referrals.

<sup>2</sup> Please note that all are mutually exclusive, with multiple impairment costs highlighted

**IMPORTANT:** Direct Payment for Referrals

It is not recommended that you raise funds to pay directly for referrals through your organisation. This is not sustainable because 1) some children may have recurrent treatment costs throughout their life spans that the family will no longer be able to afford once the project stops paying and 2) it does not build the capacity and the responsibility of the sector to make services available to children with unmet health, rehabilitative and other needs.

It may be prudent to involve your Advisory Group for assistance from service providers and to lobby for commitment from federal and local governments to support some of these costs (both direct and indirect) and be involved in long-term follow up of identified individuals.

Textbox 81: Important Information on payment for referrals

Figure 2 shows the referral mapping undertaken in Bogra, Bangladesh as an example.

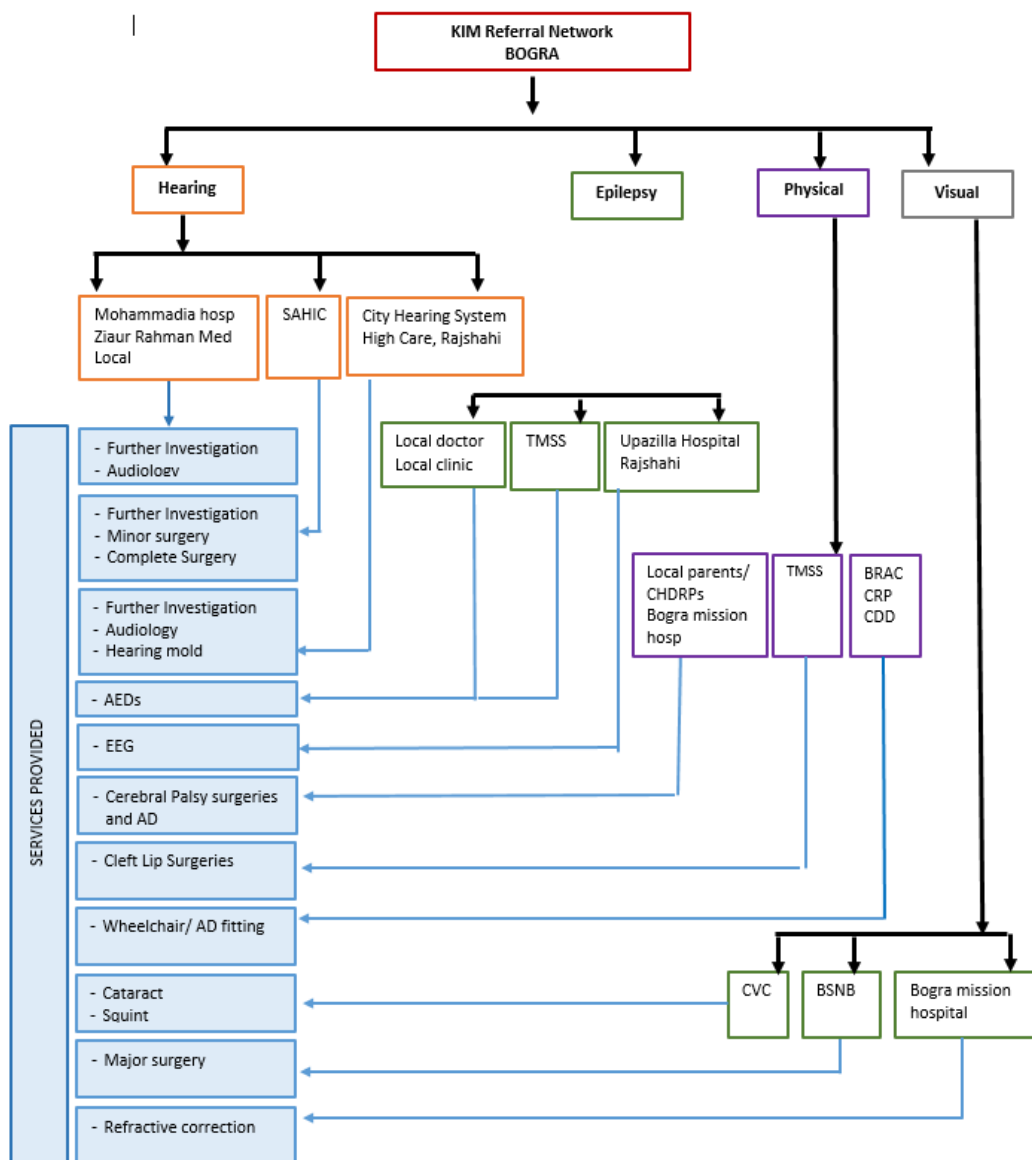


Figure 2: Referral Mapping in Bogra, Bangladesh

## 3.7 Seeking advice from the community and identifying Key Informants

### 3.7.1 Getting to know the community

Once you have determined the geographical coverage of your KIM and the services available, it is essential to spend time in each locality both communicating your intentions to local authorities and sensitising the community to disability awareness.

Ensure that a member of the project staff (either the Project Manager or a KI Coordinator) visits all local authority representatives for permission to work in the study area, and determine who the key leaders are, as well as potential obstacles and facilitators to help with planning.

Make sure to explain your purpose clearly and if possible leave a printed summary of your aims and objectives that can be circulated in community meetings – for example at religious services or in market places. It is very helpful to KIs if the community is made aware of the upcoming study in advance, and of the potential gains of the KIM.

It is important to seek advice from the community on the identification of Key Informants (see below). It is also useful when meeting community stakeholders to prepare for the KIM Sites by asking for their advice in locating a suitable venue to use as a KIM assessment site. KIM Site venues should be large, open spaces in which different screening and assessment stations can be set up. They should be cool and shaded, and have space for caregivers to wait with their children if necessary. Ideally, they should be situated in a central village location easily accessible to the majority of community members. If KIM sites are a long way from the homes of children and their caregivers, consider whether their transport to the site can be provided or whether a more convenient site can be established.



*Photo 8: Queuing for the KIM Site, Bangladesh*

### 3.7.2 Identifying Key Informants

Determining who your Key Informants will be is a crucial part of the methodology.

Key Informants should be:

- ✓ Committed to supporting their communities long-term
- ✓ Knowledgeable about people living in their communities
- ✓ Respected within their communities
- ✓ Trusted and known to be non-biased within their communities
- ✓ Diligent workers
- ✓ Literate

Furthermore, Key Informants should include both males and females, and representatives of people with disabilities.

Key Informants' core roles are:

- ✓ Identifying children with targeted impairments/health conditions in their community (or a sub-section of their community if the community is very large)
- ✓ Listing the details of these children and explaining clearly to their caregivers about the objectives of the KIM
- ✓ Giving full and clear details about KIM assessment Sites that the child and his or her caregiver are invited to attend
- ✓ Counselling and supporting caregivers who are concerned about attending KIM sites
- ✓ Reporting back and assisting in overcoming any perceived barriers to attendance raised by caregivers of listed children
- ✓ (Optional) Providing long term advocacy for disability in their communities including linking children with disabilities with appropriate services
- ✓ (Optional) Disseminating study findings in the community

Discuss these needs and roles with community leaders and ask them to assist you in naming people or groups of people who may be appropriate for KI training based on the above criteria. Ask them to determine the service providers, community leaders and other stakeholders (for example, religious and community groups, government and administrative authorities, NGOs and private sector groups) who contribute to and are well known/respected by the community.

### 3.7.3 Working with existing community worker schemes

Community health or outreach workers may be good KIs if they are already operational in the district in which you wish to conduct a KIM. Pre-existing community worker schemes can foster long-term links between the community and disability services, and KI training



may be complementary to their original skill set and mandate. Similarly, community volunteers will already have a good baseline knowledge of the community. However, pre-trained community workers may have less time available to commit to identifying children with disabilities on top of their established roles. It is therefore crucial to assess the time availability and commitment of any potential KIs (see Textbox 12, below).

If you decide to work with existing community workers or volunteers, ensure to respect the current structure and hierarchy of their work. Discuss your request with relevant organisation heads and request permission from supervisors to conduct additional disability training amongst the group. Request information on the most appropriate way to incorporate volunteers.

#### **Example: Working with pre-existing community worker schemes**

In a KIM conducted in India by one of ICEDs partners, the team decided not to offer payment for a day's training on disability to Accredited Social Health Activist (ASHA) community workers given that this was not the current expectation. In Malawi, in contrast, KIs were paid a direct stipend to ensure their ongoing commitment to the work. Given their other roles and responsibilities, the Malawi KIM coordinator felt that without an incentive the work would not be completed. Note that this had significant budget implications for the project.

Similarly, in Pakistan KIs were predominantly chosen from the pre-existing Lady Health Worker (LHW) scheme. The KIs did not adequately identify all children with disabilities in their communities and it was felt that they were perhaps already overburdened and unable to fulfil this additional task.

*Textbox 92: Example of working with existing community schemes*

### **3.7.4 Stakeholder incentives, boundaries and recruitment**

Depending on the context, you may need to consider providing incentives to local leaders and stakeholders to help you identify KIs. Previous KIMs have benefited from no more than a 1:100 ratio of KI to community members. Discussions with community leaders and local authority maps and censuses should help you understand the rough size of each community within your study area and the number of KIs you need to identify from each.

You will need to determine specific geographic boundaries within which each KI should operate. In rural settings, one KI per village may suffice. In areas with high



*Photo 9: KI Training, Bangladesh*

population density, it may be necessary to identify more than one KI per village to achieve the 1:100 ratio. You will need to provide each with distinct boundaries so that they do not overlap. KIs should only be asked to identify children from within their own extended community, and not to travel to communities they do not know. This is because the strength of the methodology lies in the social network of KIs and their knowledge of and respect within their own communities.

You will then need to contact (via KI Coordinators) each identified potential KI and explain clearly the requirements of the role. If the person agrees to take part, ask them the dates that they are available and explain that you will confirm the training date once you have spoken to remaining potential KIs and identified the most suitable date. Local authorities can assist in identifying a community hall or school in which to conduct the training.

#### **KEY POINTS FROM THIS SECTION:**

- Determine that a KIM is right for your needs by holding a planning meeting and addressing key questions (Section 3.1)
- Establish an advisory group of disability stakeholders to provide contextual input, technical advice, local knowledge and local ownership of study (Section 3.2)
- Attain all necessary permissions and keep these with you at all times (Section 3.3)
- Identify a competent project manager and train a cohort of dedicated, paid KI Coordinators (Sections 3.4 and 3.5)
- Map and coordinate onward referral pathways for children identified in the study, making sure not to establish a dual or independent service as this is not sustainable (Section 3.6)
- Establish MoUs with service providers and lobby for lower cost or free service provision where possible (Section 3.6)
- Identify Key Informants with the help of community leaders who can also help identify KI Training venues and KIM Site locations (Section 3.7.2)
- Consider working with pre-existing community worker schemes but be aware of the risk that they will not have the capacity to fulfil the role (Section 3.7.3)

*Textbox 13: Key Points from Section 3*

## 4. Key Informant Training

The following section provides practical tips and considerations for training KIs, including preparations, training materials and content. It also includes recommendations on how to empower KIs to advocate for disability in their communities long term.

Good training of KIs is imperative to the success of the KIM. Badly trained KIs may not identify all children with disabilities (meaning that the data cannot be used to estimate prevalence), and will be less invested in relaying accurate information and encouraging those that have been identified to participate in assessment sites (leading to greater risk of children with disabilities not accessing available and appropriate services).

### 4.1 Considerations when training Key Informants

#### 4.1.1 Preparations

It is the responsibility of the project manager and KI coordinators to finalise the preparations before beginning to train KIs. This includes the following key points:

1. Ask members of your advisory group or other disability stakeholders and representatives to explain how disability is defined in the community/society. This includes local terms used, what these mean and how disability is understood at the community level. This will give you an idea of how disability is perceived by the KIs and whether there are any prevailing misconceptions or stigmas about disability.
2. Develop an overview of disability legislation in the country, and whether or not the country has either signed or ratified the CRPD. Does the country have a national plan on disability and any legislation, policies or concessions related to health, education, social welfare or vocational training for adults and children with disabilities? This is important background information for you to know, and also important information to share with Key Informants as background for training sessions on disability rights and as part of their potential ongoing role as advocates for disability in their communities.
3. Organise for a representative from a local Disabled Persons' Organisation (DPO) to attend the KI training sessions where possible and explain to Key Informants the stigmas surrounding disability and challenges faced by people with disabilities in their country. A local perspective will be more engaging for KIs as it will be easier for them to relate to the issues raised.
4. If you have the time and resources, consider updating the photos and sketches in the KI Training flipcharts to match the local context with the help of your advisory group.

Depending on the impairments/health conditions you are targeting, you may also need to add/remove certain parts of the flipchart. It will also really help if you are able to translate the flip chart into the local language and use locally understood terms to describe the impairments and health conditions covered.

[Link to KIM Malawi Flipchart](#)

[Link to KIM Bangladesh Flipchart](#)

Please note that the above files are in PDF to compress sizes. Contact [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk) if you would like a PowerPoint version of these flipcharts emailed to you.

5. Determine a training schedule – Unless the KIM you are planning is very small and all of your KIs can be trained at once, it is likely that training will have to be done in phases. Work out which communities you wish to conduct training in on which dates, and arrange a schedule with the help of local stakeholders who can help you identify training or community halls. If you do not prepare this in advance it will quickly become a logistical struggle to juggle the practicalities of different training sessions at once.

#### 4.1.2 Determining KI incentives

Decide what incentives to offer KIs for participation in the study and ensure to budget appropriately for this.

Possibilities include:

- Direct payment for work completed
- Work completed on a voluntary basis but training payable
- Work completed on a voluntary basis but transport costs (to training and to identify children with disabilities) covered
- Work completed on a voluntary basis with all costs incurred by the individual

The most appropriate choice will depend on the local context, the employment status of the KIs and the distances that KIs have to cover both to identify children and to attend training. In all cases, you should offer non-monetary incentives such as shirts, pens, bags and all materials needed to complete the work (data sheets, clipboards etc.). All KIs for the project should be treated equally and offered the same incentives.

Determine whether any assistance can be given to caregivers and their children attending the study. As previously discussed, it is not advisable to directly fund referral services. However, if parents accrue personal costs (such as transportation or childcare for other children under their care) in bringing their child to KIM Sites, it is prudent to determine whether any of the stakeholder organisations are able to either assist in these costs or arrange transportation of caregivers and children from their homes to the KIM Site. These costs have previously been determined to create significant barriers to KIM Site attendance. KIs will need to know this information in advance to be able to relay the correct message to children and their caregivers that they identify.

### 4.1.3 General tips for KI Training

Each KI Training session lasts one full day. The optimum size of each training will depend partly on the population density of the area you are covering and how far KIs have to travel to attend. Ideally, KIs should be trained in groups of approximately 20 to ensure enough time and space for any questions or comments that arise.

It is important to make the training participatory and to give KIs time to ask questions and clarify doubts or confusion. Use ice-breakers (such as asking KIs to introduce one another, or one another's understanding of disability).

### 4.1.4 Recording KI profiles

Keep a record of all the KIs who attend each training, including basic demographics such as location, age, gender, education level, and disability status. As well as for your records, you can also use this information after data collection has finished to analyse whether there were any differences between KIs in identifying children with disabilities (e.g. number of children listed, proportion of children listed screening positive, dropout rate). KIs should have a unique ID code that can be attached to any lists they return, again to monitor which KIs are referring which children and in what numbers

A KI Profile sheet developed for KIM Bangladesh is available and can be adapted for your needs. Download [here](#).

## 4.2 Key Informant Training Content

The exact content for KI Training will depend on your reasons for conducting a KIM and your specific resources and setting. However, key areas to cover in a one day KI training, with rough time allocation for each section are explained below. Note that some activities (who you are, the KIM and disability concepts) are the same as the training provided to KI Coordinators. KI Coordinators should consequently be very familiar with the material and comfortable using it to train KIs.

### 4.2.1 Example KI Training Timetable

#### **09:30 – 10:00**

#### 1) Who you are and why you are undertaking a KIM

Explain clearly the purpose of the KIM and your rationale for coordinating one. It is critical that KIs are fully aware of the reasons behind their recruitment so that they can explain this clearly to participants and to foster their commitment to the role.

## 10:00 – 11:30

### 2) Key concepts about child disability including breaking down stigmas

Use the same methods as in the KI Coordinator Training: use participatory and questioning methods to ask KIs what they understand about disability – what causes it, what impact it has, and what rights children with disabilities have. You can use the UNICEF “It’s About Ability” Guide again, and also the “Disability Information and Awareness Notes” for KIs on our website (link to document [here](#)).

As with KI Coordinator training, see if you can identify a representative from a local DPO or disability Self Help Group in assisting you in this section from a local perspective.

Play the Game of Life (as in KI Coordinator Training) – link to Guide [here](#).

This component of the training is critical in breaking down prevailing stigmas and ensuring that your KIs have some understanding of a rights-based approach to disability before identifying children with disabilities in the community (See Textbox 14, below).

#### Defining Disability Stigma

Prevailing attitudes in many low resourced settings may include belief that disability is the “will of God”, either as a test or as punishment for sins committed by current or previous generations[10]. Other cultural stigmas, such as the belief that people with disabilities create a “social burden” may be deeply ingrained and it is imperative that sufficient time is dedicated in training to challenging and overcoming these attitudes. If not, KIs can mistakenly perpetuate these attitudes to the detriment not only of the KIM but of children with disabilities in the community.

Be sure to explain if local terms used to describe disability are unfair and do not respect the individual. Often, informal terms used to describe disability can be pejorative and undermining, and it is important to explain why these terms are not appropriate, even if commonly used.

*Textbox 14: Defining Disability Stigma*

## 11:30-13:00

### 3) Identifying target impairments/health conditions in the community

Using your own methods or a KI Flipchart such as the ones developed for previous KIMs, explain to KIs the criteria that they should use to identify children with targeted impairments/health conditions in their communities. The full KIM Malawi and KIM Bangladesh KI Training Flipcharts are available [here](#). These can be used as they are or adapted to your needs. See Textbox 15 on the next page for an example of how the flipchart works in practice.

You should also use this session to introduce KIs to the KI Lists that they will use to write down the names and details of all children that they identify in their communities that meet the target criteria. The list should include space for the KI to write their name and KI Code on, along with the date and name of the village.

Details that should be recorded for each child are:

- Child's name, age and gender
- Child's perceived disability
- Primary caregiver's name and contact details
- Child's address (or location of child's house if no house/street name)
- Whether the child faces physical barriers to attending a KIM Site and needs to be assessed at home by the clinical team
- A column to be filled in at the KIM site on whether the child attends or not

The KIM Bangladesh KI List is available to download [here](#).

### Example: KI Training Flipchart in Malawi

Slides on the left are the back of the flipchart, visible to the KI Coordinator. Slides on the right are the slides visible to the trainees whilst the KI Coordinators explain.

#### Cerebral palsy (CP)

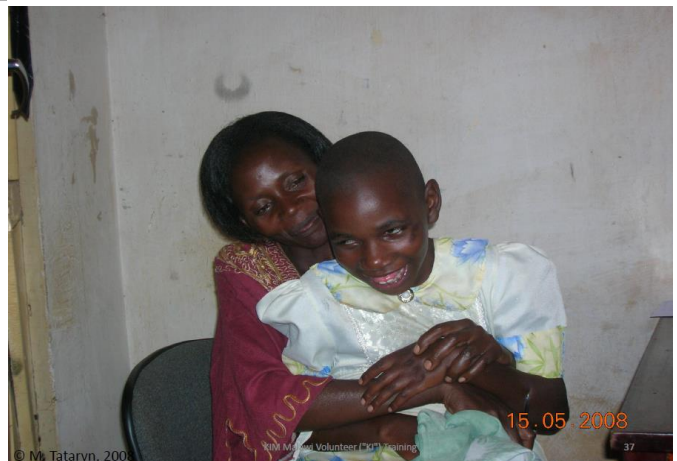
- A child has difficulty controlling his or her movements; some limbs may be very stiff; they may have trouble holding up their head
- A child may be unable to speak, or to speak clearly



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#### Even more specific conditions:

##### Hydrocephalus

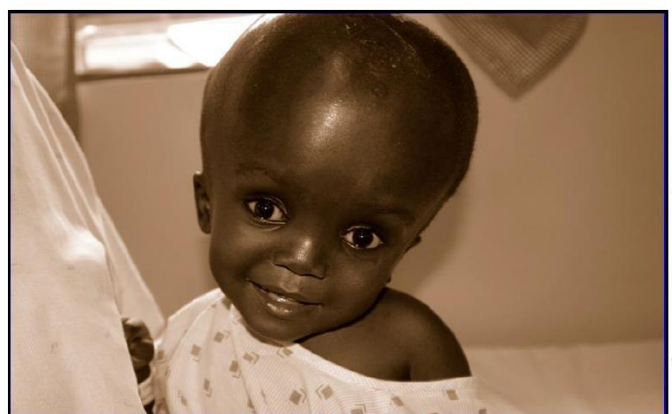
- Hydrocephalus will be clear at birth or during the growing stage
- Their head is much larger than their physical structure
- The child's head growth is quicker and abnormal for their body
- The head looks much bigger than other children

##### Microcephalous

- A very small head for that child's age
- May mean that the child will have problems understanding and learning or other developmental difficulties

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Textbox 15: Example of KI Training Flipchart

#### 4) Case Finding

At least one and a half hours in the training should be devoted to practical explanation to KIs on the best way to identify children with disabilities in the community. Previous KIMs have used the following approach for KI identification of children with disabilities in their community:

- KIs begin by spreading messages about the study and the aim to identify children with disabilities throughout the community – e.g. at schools and religious meetings, market places etc.
- KIs share these messages specifically with other stakeholders identified in community mapping to begin building lists of children believed to have targeted impairments or health conditions
- KIs then perform house-to-house visits to meet children who have been identified either by stakeholders, their caregivers or other community members as potentially having a disability. Note that you should discuss the best time of day for visits when households are likely to be available – in many cases this is early evening.
- Based on their training (and hand-out if applicable), the KI then determines whether they think that the child has an impairment or health condition meeting the criteria targeted in the training
- If so, the KI records the child's information on their KI List and gives all the relevant details of the KIM Site or other planned follow up to the caregiver. The KI should also always record whether there are any physical barriers to the child attending the KIM Site (e.g. not mobile/ confined to bed) and therefore needs to be assessed by clinicians at the house
- It is extremely important that KIs are clear that the KIM Sites are for screening and referral, not direct treatment of impairments. False expectations can cause confusion, upset and have a negative impact on how parents perceive their child's disability and their treatment-seeking behaviour
- KIs should also report any concerns voiced by caregivers of listed children back to the KI coordinator. For example, if caregivers feel they do not have the time to attend the site, or the transport costs are too high, the KI should always inform the KI Coordinator so that steps can be taken to either screen the child at home, re-arrange for smaller camps at more frequent intervals or provide further counselling.



### Example: Low KIM site attendance in KIM Malawi

Only 50% of children listed by Key Informants in Malawi attended a KIM assessment site, compared with over 90% of children in Bangladesh. In-depth interviews conducted by the team to understand why revealed that miscommunication about KIM site logistics, and financial and logistical difficulties in attending the KIM sites, were common barriers. This confirms the importance of giving clear information to KIs on the logistics of where and when KIM sites will take place, and the requirement that KIs provide support to caregivers on accessing the KIM sites. KIs also play a crucial role in explaining the purpose of the KIM site to caregivers and making sure there are no false expectations regarding service provision and that disabilities can according to misconceptions be “fixed”.

*Textbox 116: Example of low KIM Site attendance in Malawi*

### 15:30-17:00

#### 5) Explanation of next steps

Be very clear how long KIs have to identify children (3-6 weeks has worked in previous KIMs) and how much support they can expect from the KI Coordinators. This should include regular phone calls to check on KIs’ progress and assistance in clarifying any confusion. KIs should also be given the time, date and location of the KIM Site at the training, and be informed of any concessions that are being offered to caregivers for attendance, so that they can pass this information on clearly to children’s caregivers.

You should make sure that the training session is relaxed and informal, but that the KIs fully retain the key messages, highlighted in Textbox 17, below. Make sure to provide lots of time for questions and discussions, and consider short role plays or quizzes towards the end of the day to check how well the KIs have understood the training.

Depending on the literacy level of KIs, a short manual or booklet for them to take home may be very useful for ensuring key messages are retained.

### KEY MESSAGES FOR KEY INFORMANTS

- What KIM is and why you are doing it
- Children with disabilities have the same right to go to school and participate in their community as other children, but sometimes are not able to do so because of barriers
- Children with disabilities may also have unmet health or rehab needs related to their impairment
- KI role is to identify children in their communities who meet criteria of training
- KIs feel confident in identifying children with targeted impairments or health conditions in their communities based on training criteria
- KIs are clear on the next steps and the support available to them



*Photo 10: KIM Malawi Field Team*

*Textbox 127: Key Messages for KIs*

## 4.3 Key Informant Training Materials

An online repository of KIM Training Materials is available [here](#).

This includes:

- [KIM Malawi Flip Chart](#) (English and local language)
- [KIM Bangladesh Flip Chart](#) (English and Bangla)
- [KIM Bangladesh disability information and awareness notes](#)
- [KI Profile Sheet](#) (to record basic demographics and ID numbers of all KIs)
- [KI Lists](#) (for KIs to record all the children in their community that they think meet the criteria)

We encourage other organisations conducting KIMs in different settings to share their resources with us so that this repository can be strengthened with country or region-specific materials. Materials can be emailed to [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk)

## 4.4 Supporting Key Informants in Identifying Children with Disabilities

Regular communication between KI Coordinators and KIs is extremely important to support them in identifying children with disabilities in their communities and ensuring maximum commitment and coverage.

If you have the resources, consider giving them each a GPS machine to record the GPS location of each child listed, in case of nonattendance. Alternatively, consider whether KI Coordinators can visit each child listed by KIs in advance of the KIM Sites to verify whether the child meets the target inclusion criteria, follow up on logistics for KIM Site attendance and take a GPS coordinate reading. In Bangladesh, KI Coordinators visited each listed child prior to KIM Sites, which minimised the number of children without disabilities erroneously referred to the KIM Sites and ruled out duplications in which the same child was listed by separate KIs. It is important to cross out duplicates, otherwise you may falsely believe at the KIM Sites that a child has not attended even if they have. If you decide to include home-visits, you will have to budget for this from the project outset.

If home-visits by KI Coordinators are not possible, perhaps consider holding a meeting one week prior to the KIM Site in which coordinators and KIs can go through the registries to check for duplications and errors and re-contact all caregivers with information on the KIM Site location and time. This is a good opportunity to check that caregivers have been given accurate information about the KIM Site itself and also the potential outcomes. Ensure also to ask whether the caregivers have hesitations or barriers to attendance (such as transportation costs, or organising child care for other children under their care) and to assist where possible in mitigating these.

Contacting caregivers also helps with planning as it will allow you to know how many children are expected at the KIM Sites. If for example this number is higher than you think your clinical team can see each day you can plan an additional “overflow” KIM Site or expand the KIM Site over two days. To learn more about estimating how many people the team can see each day, see section 5.2.3 “Conducting a Pilot Test”.

#### 4.5 Looking beyond the KIM: Empowering KIs to advocate for disability inclusion

Depending on the characteristics of the individuals you have recruited to be KIs, consider whether they have the interest and capacity to take on a longer term role as a disability advocate in their community beyond the project’s completion. In KIM Bangladesh, for example, KIs expressed interest in continuing to identify and refer children with disabilities to appropriate services beyond the life-span of the project, and in particular with sharing their own learning about disability inclusion with the rest of their communities.



*Photo 11: Original KIs re-trained as KI Trainers to train other KIs on Community Feedback Sessions*

Key learning outcomes from KIM Bangladesh included that stigma was a big problem and that caregivers had limited information on available services and government provisions for children with disabilities. Consequently, 12 original KIs were given a Training of Trainers and supported to retrain a sub-set of 200 further KIs to conduct “Community Feedback Sessions” based on these key learning outcomes from the study. KIs were equipped with the key messages on disability inclusion and a booklet containing both the contact and cost details of available services, plus clear instructions on

accessing the government disability provision card. KIs were also given training on how to relay these messages to the communities.

This can build an ongoing link between the community and available services, and is particularly sustainable if your purpose in conducting a KIM is for programmatic purposes and KIs can continue to refer children identified with disabilities to a specific inclusive programme or service (such as a linked CBR programme). Moreover, if your primary purpose for conducting a KIM is to enrol children with disabilities in an ongoing programme, a long-term disability advocacy and community linkage role should be a core component of the method.

#### KEY POINTS FROM THIS SECTION:

- Good training of KIs is imperative to the success of the KIM and to identifying all the children with targeted impairments in the study communities
- Develop a sound understanding of local perspectives of disability and disability related policies before organising KI training, so as to equip KIs with the right knowledge to promote disability inclusion in their communities (Section 4.1.1)
- Consider whether it is appropriate to offer incentives to KIs for undertaking the work and if so what these are (Section 4.1.2)
- Give KIs a unique ID code and create KI Profile sheets to keep a record of the demographics of each KI who attends the training. This information can be used after data collection to analyse if there were any differences between KIs in identifying children with disabilities. (Section 4.1.4)
- Each KI Training should last 1 full day and be run by one KI Coordinator for approximately 20 KIs at a time (Section 4.2)
- How to identify children with disabilities, and how to support children with disabilities in attending KIM Sites (including what the KIM purpose is, giving clear information on KIM Site dates and venues, and whether there is transport support) are key elements of KI Training (Section 4.2)
- All KI Training Materials are available on the ICED website (Section 4.3) for use and adaptation
- Support of KIs from KI Coordinators is crucial to the project's success (Section 4.5)
- KIs can become long term disability advocates and provide an ongoing link between the community and services (Section 4.4)

*Textbox 138: Key Points from Section 4*

## 5 KIM Assessment Sites

This section provides information on how to plan for and conduct KIM Assessment Sites to determine whether children listed by KIs have disabilities, to address their unmet needs and to gather further pertinent information on childhood disability and the impact this has on children's lives.

### 5.1 Clinical Screening and Assessment of identified children

It is important to formally assess all children identified by KIs to have presumed disabilities to:

1. Confirm whether or not the child has an impairment or targeted health condition
2. Assess the type and severity of impairment or health condition causing the disability
3. Identify both met and unmet needs related to the child's disability (health, rehabilitation, education, vocational training etc.)
4. Determine whether the child experiences activity limitations or participation restrictions related to their impairment
5. Refer the child to appropriate services based on needs

If you are undertaking a KIM with the purpose of identifying children with disabilities for inclusion in a specific programme (e.g. a CBR programme), you may not feel the need to hold Assessment Sites and may prefer to undertake a needs assessment of the child in a different way (such as a home visit or in a local central area). If possible, you should still try to keep a record of which children amongst those listed by KIs are determined on assessment to have a disability. These figures can be useful for advocacy and planning future and complementary services.

#### 5.1.1 Key Informant Assessment Reliability

Previous KIMs have shown that well-trained KIs are very effective in identifying all children with disabilities in their communities, and that these estimates can be comparable to those from a household survey at a fraction of the cost[7]. However, KIs sometimes list children who, on assessment, are determined not to have moderate or severe impairments/health conditions as targeted in their training. In a small number of cases (and in more if KIs have not been well trained) they may list children who have no health or rehabilitation needs.



Photo 12: KI listing children, Pakistan

If training has been completed well, it is more likely that KIs will also list children with chronic health conditions or impairments that you haven't targeted. Any estimate of child disability prevalence must therefore be based on confirmed status after the child has been assessed by a competent medical or paramedical team. Estimates derived purely from KI lists would be considerably inflated and not reliable. See Textbox 19 below for an example of KI Reliability from Bangladesh.

#### Example: Key Informant Assessment Reliability

In KIM Bangladesh, KIs listed a total of 4128 children. Of these, 3719 (90%) attended a KIM Site. Amongst these:

- 63% screened positive as per study criteria
- 24% screened negative as per study criteria but positive for non-targeted or mild impairments, or chronic health conditions
- 8% screened positive for acute illnesses
- 5% were determined not to have an impairment or health condition

*Textbox 149: Example of KI Reliability from Bangladesh*

## 5.2 Personnel Requirements

To successfully run a KIM Site you will need at minimum to have a competent team of dedicated field staff and clinically trained professionals capable of screening, assessing, and diagnosing all impairment types that you wish to screen for. If you are collecting other data on the children's lives and access to services/social participation and inclusion, you must also have adequate field staff to conduct these interviews.

Irrelevant of the population size that you are covering, the turn out to KIM Sites tends to be high. In Bangladesh, over 100 children were seen per day and in Malawi almost 200.

Core members of the KIM Site team include:

Project Team	KIM project manager KI Coordinators
Clinical Team	Paediatrician Physiotherapist/orthopaedic specialist Ophthalmic Nurse/Ophthalmologist Ear, Nose and Throat (ENT) nurse/ surgeon
Non Clinical Team	CBR or Community Disability Worker (in all instances where available) Counsellor
If available/ applicable	Rehabilitation technician Nurse Neurologist

	Psychiatrist Fieldworkers to assist with Site coordination, screening for impairments and conducting non-clinical interviews
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Depending on your setting and resources, it may not be possible to identify clinical specialists (such as psychiatrists or neurologists) that are available and willing to participate in KIM Assessment Sites.

See Section 5.4 “Screening and Definitions” on screening techniques previously used in KIM that can be conducted by non-clinical personnel. It may be more feasible to use screens that non-clinicians can be trained to administer and to refer children who screen positive to specialists for further assessment and diagnosis beyond the KIM Assessment Site. However, a secondary referral may mean that you lose some children and their caregivers to follow up, who may find the time, cost or distance too much to attend. You need to decide which is the best option based on the resources available to you and the local context.

### 5.2.1 Home visits

If you are covering a small area or identifying children with disabilities for enrolment in specific services, it may be more appropriate to conduct home check-ups of children listed by KIs rather than holding KIM Sites. For example, in KIM Kenya (in which the primary purpose was to identify children for a case-control study on disability and access to nutrition) each child listed by KIs was visited by a paediatrician and an interviewer who used a self-reported screen and general examination to validate the child’s disability status, and the child’s referral needs. Remember that it may also be necessary to visit some children at home even if you are holding a KIM Site, in cases where children are physically incapable of attending due to existing barriers.

In previous KIMs, a significant number of children from outside the communities included in the KIM have attended KIM Sites. These are children neither identified nor listed by KIs who self-present at KIM Sites when caregivers from other areas (or potentially covered areas, if your KIs are not identifying all children with disabilities in their communities) become aware of the KIM through community networks and discussions. Many of these children may have unmet health and rehabilitative needs and would not have been identified if you assessed children via home-visits only. Note that for research prevalence estimates you would not include children who had travelled from outside the project area in the data analysis, but that you should always provide all available screening and assessment services to any child who attends an assessment site with unmet health needs, whether they were listed or not.

## 5.2.2 Training Requirements for Field Staff

Due time and energy should be given to ensuring that both clinical and non-clinical team members are confident about the screening and assessment protocol. If not, the data that is collected will not be comparable and may not be reliable.

If you have adequate budget, it would be useful to employ 2-4 non-clinical fieldworkers to assist with KIM Site logistics, screening and non-clinical interviews. KI Coordinators on their own may not have the capacity to simultaneously assist in screening, interviewing and organising the KIM Sites, which can result in longer queues and greater risk of data being missed or hastily completed.

Training of clinicians should be undertaken by clinical specialists, ideally with previous fieldwork/survey experience. This is important in case the clinical team members have specific questions related to diagnoses and interventions related to their speciality. Please contact [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk) if you would like help in identifying clinical specialists from your region to help in training.

At least a week should be dedicated to training clinical and non-clinical team members and establishing a rapport amongst team members. An example 6 day training schedule for the full Field Team (including KI Coordinators and non-clinical fieldworkers) is available [here](#).

The example training schedule assumes a full KIM is being undertaken that will include screening for physical impairments, visual impairments, hearing impairments, intellectual impairments and epilepsy. It assumes a cohort of 4 fieldworkers (1 for vision, 1 for hearing and 2 for non-clinical modules) and the availability of a paediatrician, physiotherapist, ophthalmic nurse or assistant and ENT nurse or assistant. If your field team is different to this, please adjust the schedule accordingly. Contact us on [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk) for additional advice on training.

The following resources on the website will assist you in planning your training:

- [Example Questionnaire – Clinical Modules](#)
- [Example Questionnaire – Non-Clinical Modules](#)
- [Clinical Screening and Assessment Tools and Protocol](#)

You can use these resources as a template to determine a training programme that covers the different screens and examination protocols that you will undertake. Make sure that you have the resources necessary before attempting to follow through with the sample protocol and that you adapt it to the team that you have recruited and equipment and personnel that you have available. Read Section 5.4 “Screening and Definitions” to determine exactly what protocols you want your field team to follow.

As you will see on the schedule, it is important that the team have a chance to practice working together and understanding how the KIM Sites will work in practice. Simultaneously, the schedule allows time for separate sessions in which each field team member has further training on their specific role.



The training should be completed by the KIM Project Coordinator, with the assistance of clinical specialists and a representative from a local DPO.

### 5.2.3 Conducting a Pilot Test

It is important to hold a short pilot/test KIM Site to observe how the team interacts with one another, to ensure that they are following all protocols and to estimate the number of children your team are capable of screening per day. Organising a pilot/test KIM Site means bringing together your entire clinical and non-clinical team to test how they work together and how many children they are able to assess each day. This can be used to set a “maximum threshold” of how many children can be seen by the team per day and help you to plan KIM Sites. For example, check the number of children listed by KIs against this threshold to determine whether you need to hold KIM Sites over multiple days to screen all listed children.

Depending on your resources and networks, you might be able to conduct the pilot assessment at a local school or in a local community that is not included in the main KIM community sample. You don't need to have a large number of children present, but it is helpful if you can work together with an organisation supporting children with disabilities so that your clinical team have the chance to test the skills developed and protocols shared during training.

## 5.3 Logistics of KIM Site organisation

KIM Site logistics hinge on keeping clear and updated records of children listed, their attendance and the outcome of attendance. KI coordinators and the KIM project coordinator should take responsibility for overseeing and organising KIM Site logistics.

Plan in advance who amongst your team will be responsible for specific tasks within the KIM Sites. Table 3 gives a suggested task distribution based on previous KIMs that you can use or adapt.

### **Key Point: Explaining referrals**

It is really important that you give caregivers time to ask questions about any referrals that you have provided, and make sure that they are clear on what they have been referred for and all logistics related to them getting to and receiving the service. You should make sure that they have all the necessary information related to costs, distances and exactly what they can – including potential outcomes. It is very useful to position the counsellor or community worker at the end of the assessments so that they can spend time talking through any referrals with caregivers that other members of the team have provided and making sure that they are clear about what they are being offered.

*Textbox 20: Explaining Referrals*

KIM Site Roles and Responsibilities	
Team member	Role
KI Coordinators	<ol style="list-style-type: none"> <li>Registration <ul style="list-style-type: none"> <li>Check child's name against KI List <ul style="list-style-type: none"> <li>Child is on list: Tick child's name off list as having attended and give child blank assessment form. Copy child ID from blank form to original KI list.</li> <li>Child is not on list: Do not give the child an assessment form but send them to clinical team for assessment</li> </ul> </li> </ul> </li> <li>Explain KIM Site procedure and take informed consent</li> </ol>
KI Coordinators/ Field workers	<ol style="list-style-type: none"> <li>Screening for targeted impairments/health conditions</li> <li>Non clinical modules (education, activity and participation, service access)</li> <li>Checking all forms for completion and ensuring caregiver and child are satisfied with KIM Site experience</li> </ol>
Clinical team	Examinations, diagnoses of impairments and referrals
Community Disability Worker	Non clinical disability referral
Counsellor/ KI Coordinators	Counselling and explanation of referrals and next steps for caregivers and children

Table 3: KIM Site Roles and Responsibilities

## 5.4 Screening and Definitions

Consistent screening protocols using definitions based on international guidelines should be used to assess impairment/health conditions and their severity at KIM Sites. This improves the quality and usability of the data, maximising its potential use not only for your own organisations but also other organisations and stakeholders who can benefit in the future from the findings.

The section below contains guidelines for assessing presence and severity of health conditions/impairments that have been used in previous KIMs. References are also given for each protocol.

### Example: Unique ID codes

A simple way to create IDs is to give each clinical KIM site a unique identifier (e.g. from 01 to the number of the final KIM site) and then give each child an identifier based on order of registration. Their ID code is then the KIM site code + their registration code and will be unique for each child. Add district/region codes if necessary.

Textbox 21: Example Unique ID codes

A full 30-page screening and examination protocol, based on previous KIMs, is available [here](#). The protocol gives details on how each screening is conducted and what equipment is needed. All screening tools in the protocol can be conducted by non-clinical staff, and are separate to this guide given the different ways in which you may approach screening and assessment.

There are two options for screening children for moderate and severe impairments or health conditions once they attend a KIM Site. The first (as used in KIM Bangladesh and Pakistan) is to screen each child who attends for *each* targeted impairment or health condition. This provides full and objective information on each child's functioning in each targeted area, which can be used to build evidence on child disability and ensures that even less obvious impairments or health conditions are identified. However, depending on how many impairments and/or health conditions each child must be screened for, it can take up to an hour and a half for each child to go through the entire screening process. This can cause queues if turnout to the KIM Site is high.

The second, as used in KIM Malawi, is to use a primary parent-reported screen of the child's functioning first. The reporting form used by caregivers in Malawi was a draft child disability screen currently being developed by UNICEF and the Washington City Group on Disability Statistics (see next page for more information).

A primary screen in which the caregiver answers questions on whether the child has difficulty in specific functions (such as seeing, hearing, learning or remembering) can increase the team's efficiency and ability to see larger numbers of children each day, as each team member only sees children reported to have difficulty in their specialist area. This can lessen queuing time and the time it takes each child to go through the full screening. It can also lessen the amount of time each KIM Site takes, ultimately decreasing the consultancy costs for clinical staff. However, it is possible (especially with young children) that caregivers may not be aware of or accurately report all difficulties experienced by their children. This is specifically a problem with very young children, and means that children who are at risk of having a moderate or severe impairment may not be assessed by the relevant clinical members. If your purpose is research orientated rather than programmatic, a complete screen on all children may be preferable despite the additional time and cost implications of this.

**Each of the below screens can be conducted by non-clinical staff and can therefore be carried out by KI coordinators or, if you have them, field workers.**

Remember that full protocols for each screen including instructions and equipment is available [here](#).

#### 5.4.1 Self or proxy-reported functional limitations

Several tools have recently been developed to assess functional limitations in children via proxy or self-report that you may choose to use as an initial screen before referring for specific clinical screens based on responses. If you have the time and the capacity, it would

be useful to also screen for disability using one of these tools even if screening each child for each clinical tool, for comparability with other studies and to assess reported functioning in all domains. UNICEF and the United Nations Washington City Group on Disability Statistics are currently developing such a tool, which is due for launch in mid 2015. A draft version of this tool is included in the KIM Sample Clinical Exam Form and Sample Protocol, and draft criteria to consider the child to have a disability are given below. Please check the [Washington Group on Disability Statistics homepage](#) for updates to this module and to check whether the final version is available.

Age	Protocol	Severity	Criteria
2-17	14 Questions on difficulties with specific domains. Scaled responses: no difficulty, some difficulty, a lot of difficulty and cannot do	n/a	At least one basic activity domain (Q1-8) "a lot of difficulty" or "cannot do"

#### 5.4.2 Impairments

##### Visual Impairment

Age	Protocol	Severity	Criteria
0-1	Fix and Follow using torch light or pen	n/a	Child cannot fix on and follow a moving object (torch or pen)
2-4	Counting Fingers – copying the number of fingers raised by screener	n/a	Child cannot count fingers at 6metres (approximately equivalent to VA<6/60)
5-17	Visual Acuity (VA) Measurement using 'Tumbling E' Snellen Chart	No imp.	VA >6/12
		Early	VA <6/12 and >6/18
		Moderate	VA <6/18 and >6/60
		Severe	VA <6/60 and >3/60
		Blind	VA <3/60

In previous KIMs and other surveys, moderate or worse bilateral impairment has been used as the threshold for disability. Criteria for mild and early impairments are included below for reference.

## Hearing Impairment

Age	Protocol	Severity	Criteria
0-4	Otoacoustic Emissions (OAE) tests	n/a	Fails OAE in both ears
5-17	OAE test and Pure Tone Audiometry (PTA) if OAE fails in both ears	No Imp.	<35dBHL in both ears
		Moderate	>34dBHL and <61dBHL in both ears
		Severe	>60dBHL and <81dBHL in both ears
		Deaf	>80dBHL in both ears

## Physical Impairment

Age	Protocol	Severity	Criteria
0-17	6 screening questions followed by observation of activities and history if screen positive to any question	n/a – determined by physiotherapist (see examination protocol)	

## Intellectual Impairment

Age	Protocol	Severity	Criteria
0-17	12 screening questions developed in Malawi KIM	n/a	Confirmed by clinician. Responds “no” to at least 3 of the age-relevant screening questions and/or has Down’s Syndrome, microcephaly or hydrocephaly

### 5.4.3 Health Conditions

#### Epilepsy

Age	Protocol	Severity	Criteria
0-17	Screening Questions and Seizure history	n/a	History of 3 or more tonic-clonic seizures in previous 12 months

There may be other common health conditions that can have disabling impacts on children in the setting you are working (such as albinism). You should discuss with your Advisory Group the impairments and health conditions that you wish to target and whether they recommend including additional screens.



*Photo 13: Anthropomorphic measurement testing, Malawi*

## 5.5 Examination and Diagnoses Protocols

Examination of children who screen positive for specific impairments should be done only by qualified clinical professionals with the requisite permission to work in the study setting.

Many clinicians that you work with will not have had previous experience working in a community setting and the following general rules for clinicians are imperative:

- Carefully follow all examination protocols as per training to ensure a standardised approach
- Make sure to clearly explain to the participant what you are doing at all times, and put them at ease.
- Fill in ALL elements of clinical data forms, even if the result is negative
- Make sure participants are referred appropriately
- Be careful to fill out the examination status of each participant you examine, including whether you were unable to examine them (non response, refusal)

### **Defining Cerebral Palsy**

Cerebral Palsy (CP) is defined as a “disorder of movement and posture, due to a defect or lesion of the immature brain” [11]. Whilst CP has been classified as a physical impairment in previous KIMs, future studies should consider classifying CP as “neurodevelopmental” or simply under the classification “Cerebral Palsy” as a specific condition.

*Textbox 22: Defining Cerebral Palsy*

## 5.6 Collecting other Data

Early KIMs focused only on the impairment component of disability.

Several tools are currently in development by UNICEF and the United Nations Washington Group on Disability Statistics to accurately assess a) functional limitations and b) participation restrictions amongst children. These tools are due to be launched in mid 2015 and it is recommended that all children attending KIM Sites are also interviewed using these tools to gain a comprehensive understanding of disability and the impact of impairments/health conditions on children's lives.

### **IMPORTANT:** Proxy versus independent response

There is much debate on the pros and cons of independent response by the child versus caregiver response on behalf of the child. Whilst it may be more appropriate to pose particular questions on access to parents, questions on experience and wellbeing should ideally be posed to children.

For more information, read Theunissen, N. C. M., et al. "The proxy problem: child report versus parent report in health-related quality of life research." *Quality of Life Research* 7.5 (1998): 387-397.

*Textbox 23: Important point on proxy response*

KIM Malawi also included a question set on education access amongst children with disabilities to build information on whether children with disabilities go to school and what their school experiences are.

Other modules that may be useful to include, depending on the purpose and context of the KIM:

- Socio-economic indicators
- Access to and experience of education
- Access to and experience of health and rehabilitative services
- Awareness of rights
- Wellbeing
- Anthropometry (height, weight, middle arm circumference)

Additional modules on Activities and Participation, Education, Health and Access to rehabilitation that have been used in previous KIMs are available in Excel format [here](#).

If you intend to create your own data collection forms, make sure to pre-code responses. For example, code Yes=1 and No=2. This will greatly assist in data entry and minimise the potential for errors.

### IMPORTANT: Key Attributes of KI Listed children

Always make sure to include basic information on each child's age and gender in any data collection. This is really important for data disaggregation purposes and identifying children for follow up.

Textbox 24: Key Attributes of Listed Children

## 5.7 Referral Procedures and KIM Site exit procedures

Referrals for unmet need should only be provided by trained personnel with the requisite permissions to work in the study settings.

KIM Assessment Sites are often very busy, but it is extremely important that clinicians make sure that they explain any medical or rehabilitative referrals to participants with crystal clarity. Referrals should be appropriate to clinicians' ethical codes and best practice, and due time should be spent first by the clinician providing the referral and secondly by a counsellor or KI Coordinator in ensuring the caregiver and their child are fully informed.

This explanation should then be reiterated by a counsellor or community disability worker at the end of the screening, and the child's caregiver should be given lots of opportunities to ask questions and clarify procedures.

Key areas to cover in explaining referrals to participants and their caregivers are:

- Exactly what the referral procedure entails and what outcomes the participant can expect
- Specific contact details for the service provider and any costs associated with the referral
- Whether incremental and logistics costs in accessing the services will be covered
- Contact details of KIM personnel for caregivers wishing to follow up on information given by the project team

Clear and extensive explanations are particularly important if caregivers have low literacy levels, as they will not benefit from written information or leaflets. If at all possible, KIs should be given information after the KIM Site on which children have been referred for services, so that they can visit caregivers at a later date and confirm the referral/ answer any further questions.

Participants should be issued with a referral form or record card such as the example (right) that can be given to the referral service provider.


### Example: Referral Form

Andhra Pradesh Disability Survey  
Service Referral Card

**To whom it may concern, I \*\*\*DMHO hereby request that the following referral to your services is honoured in full (Name and Signature DHMO, Mahbubnagar)**

DATE: \_\_\_/\_\_\_/\_\_\_ NAME: \_\_\_\_\_  
SEX: \_\_\_\_\_ AGE: \_\_\_\_\_  
ADDRESS: \_\_\_\_\_  
REFERRED TO: \_\_\_\_\_  
REASON FOR REFERRAL: \_\_\_\_\_  
\_\_\_\_\_  
REFERRED BY: Name \_\_\_\_\_  
Signature \_\_\_\_\_

For any enquiries about referrals, please contact one of the following:  
SERP Mandal Coordinator (Name and Phone Number) \_\_\_\_\_  
Aarogy Mitra (Name and Phone Number) \_\_\_\_\_  
PHFI Field Coordinator (Name and Phone Number) \_\_\_\_\_

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Textbox 25: Example Referral Form



You should also give clinicians a register to fill in all referrals that are offered and provide for each the following details:

- Child's name and unique ID
- Referral given
- Service provider referred to

This is important for following up referrals to encourage and monitor take up.

After the child has been through each screen, assessment and questionnaire modules necessary, they should visit the counsellor/community disability worker to discuss any referrals and ensure that caregivers are comfortable and clear on what they have been offered.

Finally, one field team member should be stationed at the exit of the Site to collect the child's form and check this for completion. If any sections are missing, they should take the child and their caregiver back to the appropriate team member to fill the section in. It is also useful to record on the form that it has been checked, for quality assurance.

## 5.8 Follow up of children who have been given referrals

As mentioned above, there are many barriers that can prevent caregivers from taking their children to referrals offered within a KIM. Some, such as barriers related to cost and time burdens, we have already discussed (See Section 3.6 "Mapping Service Providers and Referral Networks"). Other barriers can be related to misunderstanding of information on referrals, fear of procedures or hesitation from other members of the household. Previous KIMs have benefited from providing follow up home visits to all children offered a referral, to try to overcome some of these barriers. KI can play a helpful role as members of the community to assist with remaining questions, calm fears and counsel other family members about the benefits of referrals.

## 5.9 Data Storage and Entry

All raw data should be kept completely confidential and stored in a safe, clean place. Data from each KIM Site should be stored together and clearly labelled.

Data should be entered into a purpose built database for analysis. Use a programme such as Access, which you can build consistency checks into (for example, you can set the database not to accept a response that isn't possible for a particular question). Data should be entered twice, so that the two databases can be compared and errors corrected and cleaned. Contact us on [KIM@Ishtm.ac.uk](mailto:KIM@Ishtm.ac.uk) if you would like advice on developing a data entry database for your KIM.

## 5.10 Quality Assurance

A number of measures for quality assurance are built into the methodology already outlined in this guide, including obtaining all relevant ethical clearances; providing support and cross-checking KI lists; ensuring supervision of all Assessment Sites by KI coordinators; taking informed consent and assent for participation; and ensuring an exit team to check forms for completion, reiterate referral procedures and ensure satisfaction of KIM Site experience.

Further areas in which quality can be assured include:

- Use pre-coded data entry forms as much as possible to decrease data entry errors and increase data entry speed
- Give each member of the field team (clinical and non-clinical) an ID number that they can put on each form they fill out so that you can provide extra support if they make consistent errors
- Having KI Coordinators or the project manager re-check forms for error and completion before data-entry
- Create or adapt databases for data entry with inbuilt consistency checks
- Double enter and cross check data for errors
- Manually clean data before analysis

#### **KEY POINTS FROM THIS SECTION:**

- Whether you hold a KIM Site or conduct house visits, it is imperative that children listed by KIs are then assessed formally for disability and unmet needs both for ethical reasons and because it cannot be assumed that all KI listed children meet the study criteria (Section 5.1)
- The exact personnel that you need to conduct either a KIM Site or home visits to listed children will depend on how you are completing the KIM, but a KIM Site is advised for efficiency and to minimise loss to follow up (Section 5.2)
- At least 1 full week should be spent training your full field team together, with time allocated to group training and practice, and practicing of specific roles (Section 5.2.2)
- Each member of the field team should have clear responsibilities at the KIM Site and should be identified on each form they fill in by a unique field team member ID (Section 5.3)
- Screening and assessment methods used should be rigorous and internationally validated, so that they can be compared with other findings and provide reliable data (Section 5.4)
- Non-clinical data should also be collected for monitoring and advocacy purposes, including reported functional limitations and modules related to education, health, participation and access to services (Section 5.5 and 5.6)
- Poorly explained or understood referrals are a key barrier to service uptake and meeting the needs of children with disabilities. Make sure that the caregiver is fully informed of exactly what the referral is for, given contact details of the service provider, informed of any costs that they need to meet for the referral and given details to contact the KIM Team for further advice (Section 5.7)
- If possible, ask KIs to follow up on children who have been given referrals to give further advice/support (Section 5.8)
- Data should be stored safely and confidentially, and entered into a custom-built database (Section 5.9)
- Quality Assurance can be ensured at a number of points throughout the methodology (Section 5.10)

*Textbox 26: Key Points from Section 5*

## 6 KIM results and dissemination

This guide does not give detailed specific guidance on analysing KIM data, due to the inherent individuality of any data analysis based on the organisation's objectives and rationale for data collection, alongside any of the many amendments and adaptations to the methodology that may have been made by users of this guide.

Instead, this section includes key areas to focus on in KIM reporting, as well as a template KIM Report and basic tables for inclusion.

### 6.1 Producing and circulating KIM reports

Key areas that you should seek to undertake analysis based on your data include:

- Prevalence of childhood disability (the number of children identified to have disabilities as a proportion of the childhood population covered by the KIs)
- Magnitude and severity of specific childhood impairments and health conditions
- Attendance at KIM Sites (as a proportion of children listed by KIs – note that if attendance is low you will have to adjust for this in any prevalence estimates)
- Reliability of KIs (what proportion of children listed were determined to have a disability, did any children with disabilities from within the population covered by KIs self-present without being listed)
- Previous access to services and need for services as determined by referrals
- Service needs versus available services (identified during mapping)
- Information collected from any other modules incorporated into data collection, such as on education, water and sanitation, participation etc.
- Barriers to service access

Once you have completed your analysis, even if your objectives are programmatic, you should attempt to write up your findings in a way that is accessible and beneficial for other stakeholders.

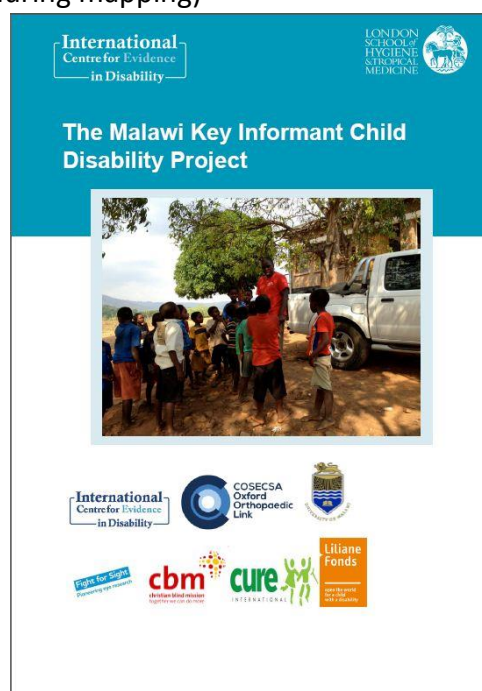


Photo 14: Cover, KIM Malawi Report

### 6.1.1 KIM Report Outline

Keep any output documents short and concise – aim for no more than 25 pages to cover the following (rough page distribution given in brackets):

1. Description of investigators, funders, members of advisory committee and other acknowledgments (1-2 pages)
2. Executive Summary: Background, Aims & Objectives, Methods, Key Findings, Conclusions and Recommendations (2-3 pages)
3. Introduction: Background on child disability in country of data collection, description of KIM and definitions used (2-3 pages)
4. Study Aims and Objectives (1 page)
5. Methods: Study Setting, Project Preparation, Recruitment of Field Team, KI Training, Identification of children via KIs, KI Assessment Sites, Screening and Assessment Protocols, Referrals, Quality Assurance, Data Entry and Analysis, Ethical Approval (5-6 pages)
6. Results: Study Population and demographics, Prevalence of targeted impairments and/or health conditions, causes of impairments/health conditions, treatment history, activity and participation (by impairment type), access to education (by impairment type), results of additional modules (8-10 pages)
7. Discussion: Summary of main findings, How information can be used, Strengths and Limitations of study (2-4 pages)
8. Conclusions and Recommendations (1-2 pages)
9. Appendix: Tools used (1-5 pages)

The KIM Malawi Report (available [here](#)), is an example on how to do this in practice and how to tailor recommendations to different audiences (policy makers, service providers and communities, for example). A selection of template tables for inclusion, with annotations, is provided in a table template document available below. These template tables are based on the data collected using the KIM Screening and Assessment Questionnaire (available [here](#)) and can be adapted to the data that you have collected.

### 6.1.2 KIM Report template tables

General notes about tables:

- Always report raw numbers (N) and percentages (%) together
- Always state when there is missing data

Table 1: Children attending the KIM Sites

Group	Number (N)	%
Children listed by KIs with suspected impairment		
Children listed by KIs attending assessment Sites		
Children with an impairment/epilepsy condition as per study definition		

Table 2: Socio-demographic characteristics of children with targeted impairments/health conditions

	N	%
Age (years)		
0-4		
5-9		
10-14		
15-18		
Sex		
Males		
Females		
District (if more than one)		
Monthly Family Income (local denominations)		
Literacy/education of parent		
Illiterate		
Can read/write		
Primary education		
Secondary education		
Currently attending school (restrict to school going age)		
No		
Yes		

Table 3: Prevalence estimates of impairments/epilepsy in study area

Impairment/health condition	Number	Prevalence per 1,000 (95% CI) <sup>a</sup>	No. Per million total population <sup>b</sup>
Physical impairment			
Hearing impairment			
Epilepsy			
Intellectual impairment			
Visual impairment			
Multiple impairments			
Any impairment/epilepsy			

<sup>a</sup> Estimating prevalence assumes that KIs identify all children with targeted impairments/ health conditions in their communities. You can estimate the prevalence, with confidence intervals, using a statistical programme such as STATA. If KIM Site attendance is low, you will need to adjust your estimates to account for this, and you must state this clearly in the report.

<sup>b</sup> Once you have determined a prevalence estimate, you can apply the proportion to a known population using available demographic data (e.g. Census or Demographic and Health Surveys). Use the demographic data to identify the proportion of the population that you are covering that are within the age criteria for your study (e.g. 0-17). You can then multiply your estimate by the proportion under 18 (e.g. x 0.4 if 40% of the total population is in this age group) and then from per 1000 to per million (x 1000) to reach an estimate per one million total population. Figures “per million total population” are very useful for advocacy and planning.

Table 4-6: Causality and aetiology of Impairments

Causes of physical impairment <sup>c</sup>		
	N	%
Congenital		
Trauma		
Neurological		
Acquired non-traumatic		

<sup>c</sup> If you have a big enough sample, it would be useful to include specific diagnoses of prevalent physical/neurodevelopmental impairments such as Cerebral Palsy and Cleft Palates

Causes of moderate/severe hearing impairment <sup>d</sup>		
	N	%
Ear Disease		
Wax		
Foreign Body		
Otitis Externa		
Acute Otitis Media		
Chronic Suppurative Otitis Media		
Serous Otitis media (with effusion)		
Dry perforation of Tympanic Membrane		
Infectious Disease		
Non-Infectious Condition		
Undetermined Cause		
Other		

<sup>d</sup> It can be difficult to diagnose exact causality of hearing impairment in field settings. Instead it may be easier to report the results of ear examination (see KIM Sample Clinical Form).

Causes of moderate/severe vision impairment		
	N	%
Whole eye microphthalmus/ anophthalmus		
Lens (unoperated cataract)		
Lens (aphakic/pseudoaphakic)		
Glaucoma/buthalmos		
Uvea		
Refractive Error		
Corneal Opacity		
Retina		
Optic Nerve		
Others/ Unknown		

Table 7: Treatment Needed

	Treatment needed	N	%	Extrapolated number of children needing treatment per million population <sup>e</sup>
Physical Impairment	Physical therapy			
	Surgery			
	Occupational therapy			
	Wheelchair			
	Medication			
	Appliance/orthosis			
	Mobility aid			
	Tricycle			
	Plaster of Paris			
	x-ray			
	Prosthesis			
	Special seating			
	Other			
Hearing Impairment	Medication			
	Hearing Aid			
	Language/Speech Rehabilitation			
	Special Needs Education			
	Vocational Training			
Vision Impairment <sup>f</sup>	Refractive Services			
	Cataract Surgery			
	Other			

<sup>e</sup> This figure can be estimated as in Table 2 (Prevalence).

<sup>f</sup> For vision impairment, treatment options can be estimated from causes



Table 8: Activity and Participation

	Max score possible	N	Average Score
Children 5-8			
Sensory			
Learning and experiences			
Communication			
Mobility			
Self Care			
Interpersonal Behaviours			
Major Life Areas			
Community, Social and Civil Life			
Children 9-16			
Sensory			
Learning and experiences			
Communication			
Mobility			
Self Care			
Domestic Life			
Interpersonal Behaviours			
Major Life Areas			
Community, Social and Civil Life			

The maximum score for each age group and domain is the total score if each question in the set is answered “unable to do”. Report the maximum possible and the mean composite participation scores for each age group.

Table 9: Education Access

Impairment/ epilepsy group	Never attended school N (%)	Odds ratios adjusted for age and sex <sup>g</sup> (95% CI)
Hearing impairment		
Physical impairment		
Vision impairment		
Epilepsy		
Intellectual impairment		
Multiple		

<sup>g</sup> If possible, report the odds of school attendance amongst children with impairments to identify any trends. For example, KIM Malawi found that children with multiple impairments were 16 times less likely to be in school than children with hearing impairments. Adapt these categories to your own data and needs.

## 6.2 Circulating and disseminating KIM reports

You should first share your findings with your advisory group, and then disseminate more broadly.

### 6.2.1 Sharing findings with your advisory group

Presenting your key findings to your advisory group (for example in a 45 minute PowerPoint presentation) first is a good way to gain feedback on how to use the findings constructively and which recommendations to focus on. You should do this prior to circulation to incorporate suggestions into any final documents. Where possible, make sure all output documents are available in accessible formats. A guide for producing accessible print and online documents is available from AbilityNet [here](#).

Key points to discuss with your advisory group prior to finalising the reports and launching the findings publically:

- What do they see as the key findings of the study?
- What do they think are the key recommendations coming from this study for policy makers?
- What are the key recommendations for service providers?
- What are the key recommendations at the community level?
- What share of responsibilities do they want to see to improve the quality of life of children with disabilities in their country?
- How should stakeholders coordinate their activities to best support children with disabilities?

### 6.2.2 Wider Dissemination

Methods for circulating and disseminating KIM reports include:

- 1) Hold a dissemination workshop at the national level

Invite key stakeholders, including members of your advisory group and wider disability stakeholders to an official dissemination workshop in a local conference room or hotel. You should seek to invite representatives of the following groups:

- High profile government officials and representatives from relevant ministries including health, education, social welfare and employment
- Key service providers including providers of general health care, rehabilitation services, education and vocational services
- Key collaborators from throughout the project
- Members of both mainstream and disability specific NGOs
- Members of Disabled People's Organisations and peer support groups
- Members of your clinical and non-clinical field team
- Other members of your organisation
- Members of public health research organisations

- Representatives from amongst the cohort of Key Informants
- Representatives from amongst the children identified (alongside their caregivers)
- Print, TV and Radio media to publicise the event and findings

If possible, invite at least one high profile delegate to attend the workshop as a “Special Guest”, and to provide their comments on the study findings as part of the workshop. This will increase interest from the media and may encourage take up of the findings. The focus here should be on the policy makers and their endorsement of recommendations from the study.

Below is a template for running a dissemination workshop, based on recent dissemination sessions held by ICED.

<b>Time</b>	<b>Speaker</b>	<b>Content</b>
10:30 - 10:45	High Profile Delegate	Welcome Address - importance of disability data collection
10:45 - 11:00	High Ranking member of organisation	Introduction to organisation that has conducted the KIM
	KIM Project Manager	KIM Study in Country xx: Introduction, Methods, Results and Recommendations for stakeholders and service providers
11:00-11:45	High Ranking member of organisation	Launch of Report
11:45 - 11:55	High Profile Delegate	Comments from Delegate
11:55 - 12:05	KIs	Comments from KIs
12:05 - 12:15	Questions from Audience	
12:15 - 12:30	Lunch	

*Table 4: Dissemination Workshop Template*

## 2) Hold regional dissemination workshop in the study area(s)

The format of regional workshops should be similar to national workshops but with a focus on recommendations to service providers in the areas that the study has been held. The format and representative list should be the same as for a national workshop, but it would also be helpful to invite community leaders and local stakeholders.

## 3) Community Feedback Sessions

The aim of Community Feedback Sessions are for communities involved in the study to learn about the study outcomes and the recommendations for them at the community level. Community sessions should be informal with verbal or flipbook presentations that are clear for communities to understand. Recommendations should be practical and useful for communities and especially caregivers of children with disabilities. See Textbox 27 for an example.

### Example: Community Feedback Sessions in Bangladesh

The KIM in Bangladesh re-trained KIs after the results had been analysed to go back into the communities involved and share important findings with caregivers and communities in general. This included sharing information on available services and benefits available to children with disabilities, which many caregivers were not aware of.



Photo 15: Community Dissemination, Bangladesh

*Textbox 27: Example of Community Feedback Sessions from Bangladesh*

#### 4) Social Media

Social media, such as websites, Facebook and Twitter can be powerful ways to disseminate your findings to larger audiences. You should always upload your reports onto your organisation's website in an accessible format. You can further publicise your results using Facebook and Twitter. The organisation [SocialBrite](#) has lots of social media tutorials for non-profits including:

- [How to Build Awareness for your campaign](#)
- [10 rules for how non-profits should use twitter](#)

### 6.3 Engaging stakeholders to use KIM results

Through your advisory group and the dissemination workshops at the various levels, you should prioritise engaging local stakeholders at all levels in using the results of the KIM to improve the situation of children with disabilities. Through the compiled evidence on the magnitude and impact of disabilities on children, work together with service providers to:

- Determine gaps in provision of services and tangible solutions
- Reinforce appropriate pathways of referral services and communication/ collaboration between service providers using information on numbers identified and interventions referred
- Assess availability of services and uptake by children with disabilities and their caregivers
- Identify and alleviate gaps in information available to caregivers of children with disabilities at the community level
- Prioritise advocacy activities based on findings

## 6.4 Using KIM data to advocate for and improve services and inclusion of children with disabilities

You may have collected important information on access to non-health services including education, alongside participation of children with disabilities in society. This information can emphasise the barriers faced by children with disabilities that can have long term impact on their quality of life and capacity for independent adult lives. Through documenting and sharing this information, you can build evidence for advocacy and inclusion of children with disabilities.

## 6.5 Long term role of Key Informants

Key Informants in Bangladesh expressed a strong desire to continue providing information and assistance to members of their communities about child disability. Whether your cohort of KIs are voluntary or already engaged in ongoing community work, it is extremely beneficial to children with disabilities to retain a long-term role of KIs in educating their communities about disability and providing information about available services and benefits.

If your KIs are voluntary consider providing a secondary round of training to share key findings and information on how KIs can continue to assist children with disabilities based on your findings (for example onward referral to paediatric centres, or assistance in claiming benefits). If your cohort is already involved in community work (and in particular community based rehabilitation), consider working together with their employers to build further capacity on prevention, early intervention and management of child disability, including referring children with disabilities to appropriate services.

#### KEY POINTS FROM THIS SECTION:

- You should always create a report of key findings in the KIM to assist stakeholders in service planning, advocacy and building evidence
- Key areas to cover include prevalence, magnitude, severity, attendance and access to service (Section 6.1)
- Reports should be kept concise (no more than 25 pages) and include simple tables (with missing data reported) for ease of reading (Section 6.1.1 and Section 6.1.2)
- Reports should be presented to your advisory group first, to gain feedback and finalise recommendations (Section 6.2.1)
- Wider dissemination of results should include a national workshop, regional workshop in the study area and community feedback sessions to participants (Section 6.2.2)
- Through your advisory group and workshops, you should prioritise engaging with local stakeholders at all levels in using the results to improve the situation of children with disabilities in the locality and increase availability of services (Section 6.3 and Section 6.4)
- KIs can be engaged in a longer term role to continue promoting disability inclusion and encouraging service access for children with disabilities in their communities (Section 6.5)

*Textbox 158: Key Points from Section 6*

## 7 Potential challenges and how to address them

The following section provides advice on addressing potential challenges that you may face throughout the KIM process, based on the experience of previous KIMs conducted by ICED.

### 7.1 High numbers of KI listed children

In KIM Malawi, KIs listed a far higher number of children that they perceived to have disabilities than had been anticipated. As discussed earlier in this guide, it is important to review KI lists in advance of KIM Sites to mitigate problems and plan “spill over” KIM Sites if necessary. If the number is extremely high, consider KI Coordinators visiting all listed

children prior to the KIM Sites to determine whether the listed children do meet the criteria or not.

Please note also that in many instances children who have not been listed by KIs may arrive with their caregivers given news spread to non-listed communities about the presence of a clinical team who can help children with disabilities. You should always try to assess any children who present with health or other difficulties, and to provide the best referrals to your ability. Make sure however to use a specific code to identify children who presented without being listed, so that you can differentiate in analysis between listed and non-listed children (for example, the latter, if coming from beyond the geographic boundaries of your KIM, should not be included in prevalence estimates for within those boundaries).



*Photo 168: Local Transport, Bangladesh*

## 7.2 Low KIM Site Attendance

There are several common reasons why children listed by KIs do not attend the KIM Site that they are invited to.

In Malawi, in-depth interviews with caregivers who had not brought their children to the KIM Sites revealed that they were confused about critical logistics such as dates, locations and KIM Site objectives. Section 4.4 describes in detail how to support KIs to make sure that they provide all the right information to caregivers about the KIM Site logistics and objectives, and report back any concerns voiced directly to KI Coordinators.

If KI Coordinators are aware of potential barriers they should consider providing further counselling to the caregiver (for example if the caregiver is not sure that the KIM Site is useful for her child, or the decision not to allow the child to attend the site has come from

another member of the household). Alternatively, if barriers are related to transport costs or time burdens, the KI Coordinators and Project Manager should discuss whether to reschedule for smaller, more frequent Sites at shorter distances from one another. Finally, consider house visits but be aware of the time and cost implications of this and that this is not feasible if covering a large population.

### 7.3 Loss to follow up

In KIM Bangladesh, referrals for children with disabilities were either provided free of charge by service providers, or funded by the KIM project donors. Despite this, only 48% of children had taken up their referrals between six and eighteen months after the KIM Sites. A mixed-methods barriers analysis was undertaken[12], identifying various barriers to referrals including:

- Focus on daily survival – child’s referral not given priority given low socio-economic means and prohibitive indirect costs of referral
- Confusion and misunderstanding of referral process
- Impairment type - children were less likely to take up services if they had vision or hearing impairments than if they had physical impairments or epilepsy

Ensuring that caregivers have the appropriate information about the exact process and potential outcomes of referrals are imperative to minimising loss to follow up. Similarly, understanding caregiver competing priorities through discussion with your Advisory Group and other stakeholders will allow you to discuss these with caregivers at KIM Sites and encourage uptake of services for the child’s wellbeing.

### 7.4 Motivating KIs

The motivation of KIs is imperative to the success of the KIM. If KIs do not accurately identify children with disabilities, findings will be incomplete and children with unmet needs will not be provided with services to assist them. Regular support for KIs, including frequent phone calls and holding meetings in advance of KIM Sites, can encourage and motivate KIs. As previously discussed, it is also important to make sure that the incentives (whether monetary or non-monetary) provided are appropriate and in line with expectations in the setting you are working in.



## 7.5 Many children screening positive for mild impairments not in target criteria

To date, KIM has been validated scientifically to identify all children with moderate or severe physical, visual, hearing impairments or epilepsy only. We do not have data that shows that KIM can effectively identify all children with mild impairments or intellectual impairments and therefore cannot assert prevalence estimates of mild or intellectual impairments.

The KIM Malawi trialled the use of a caregiver-reported screen for moderate/severe intellectual impairment. This tool has not been widely validated and we have not yet compared the ability of KIs to identify intellectual impairment versus a gold standard (e.g. population based survey of intellectual impairment in children). We welcome future work in this area however given the importance of creating a comprehensive KIM methodology that can identify all moderate or severe impairments in children.

Secondly, we know from previous KIMs that in practice, many children with mild impairments are often brought to the KIM Sites by KIs. This can create an additional burden on project teams to screen and assess all identified children. Pre-emptive home visits by KI Coordinators (See Section 4 “Supporting Key Informants in Identifying Children with Disabilities”) can minimise the number of children without targeted impairments/health conditions attending the site. However, if there is any possibility that the child has unmet health needs related to his or her mild or untargeted impairment or health condition, the child should always be invited for screening and examination so that they can be referred to appropriate services.

#### KEY POINTS FROM THIS SECTION:

- There are a number of potential challenges that you may face in conducting a KIM that previous KIMs have also faced
- Numbers of children listed by KIs may be much higher than anticipated – consider “spill over” sites and check for duplicates if so (Section 7.1)
- Conversely, attendance at KIM Sites amongst children listed by KIs may be lower than anticipated – ensure that caregivers are being given accurate and complete information, and determine whether there are additional barriers to attending if so (Section 7.2)
- Children who attend a KIM Site and are provided with a referral for unmet need may not take up the service. This may be due to confusion or misunderstanding about the referral, or competing priorities. Make sure full counselling is given to caregivers before they leave the KIM Site (Section 7.3)
- Ensure KIs are fully motivated to complete their tasks and identify all children with targeted impairments or health conditions in their communities (Section 7.4)
- It is likely that children with non-targeted or mild impairments will be identified by KIs. Home-visits by KI Coordinators in advance of the KIM Site can diminish it, but if there is any possibility of the child having an unmet health need they should always be included in KIM sites (Section 7.5)

*Textbox 29: Key Points from Section 7*

## 8 Summary

The purpose of this working guide was to share experiences of ICED and CBM in conducting KIMs in Bangladesh, Pakistan, Malawi and Kenya. The KIM continues to evolve, as do the methods of collecting data and the protocols of screening and examination.

This guide is not meant to be a prescriptive manual, but to provide advice on how KIM has been organised previously. We hope that readers of this guide will contact us for advice and to share their own KIM experiences so that the guide can grow organically. We particularly hope that this guide is useful for practitioners and those working in community-based service provision, to assist them in identifying and supporting children with disabilities in the community.

If you have conducted a KIM and used this guide to do so – we’d love to hear from you and how it went. If you have comments or feedback on this guide and whether there is missing information you would have liked to read, please contact us on [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk)

## 9 Resources

The following resources are collated on the [Using the Key Informant Method: A Working Guide](#) webpage and can be downloaded freely with this guide to assist organisations planning to organise a KIM.

- [KI Coordinator Training](#) (PDF, 45 pages, 1.3MB)
- [Full Field Team Training Schedule](#) (Word, 1 page, 18KB)
- [Sample Screening and Assessment Protocol](#) (Word Doc, 41 pages, 9KB)
- [Bangladesh KI Training Flipchart](#) (PDF, 23 pages, 1.8MB)
- [Malawi KI Training Flipchart](#) (PDF, 49 pages, 3.0MB)
- [Disability Information and Awareness notes for KIs](#) (Word, 3 pages, 34KB)
- [KI List](#) (Word, 1 page, 20KB)
- [Parent Information Sheet](#) (Word Doc, 2 pages, 35KB)
- [Child Friendly Information Sheet](#) (Word Doc, 2 pages 2.2 MB)
- [Parent and Child Friendly Consent Form](#) (Word Doc, 2 pages, 19 KB)
- [Questionnaire - Screening and Assessment](#) (Excel, 8 pages, 150KB)
- [Questionnaire - Non-clinical Modules](#) (Excel, 5 pages, 78kbKB)

Please note: the following resources are also available in editable PowerPoint version. Please contact [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk) if you wish to receive any of these as PowerPoint files:

- KI Coordinator Training Slides
- Bangladesh KI Training Flipchart
- Malawi KI Training Flipchart

Whilst we cannot provide step by step assistance in carrying out a KIM, we are happy to hear from those with specific queries or who want to share their own experience with us. If you have any questions or want to get in touch, please contact [KIM@lshtm.ac.uk](mailto:KIM@lshtm.ac.uk)

## ANNEX 1: GLOSSARY OF KEY TERMS

### Definition of “Child”

This guide defines a child as per the United Nations International Convention on the Rights of the Child as any human being under 18 years of age, unless the law of his or her country deems him or her to be an adult at an earlier age[13] .

### Definition of “Disability”

The definition of disability used in this methodology is the description of persons with disabilities in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):

“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”[14]

This definition is based on the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF, see Fig 1 below)[15]. The ICF is an interactive bio-psycho-social model of disability envisaging disability as the umbrella term to describe health conditions and body function/structure impairments, activity limitations and participation restrictions.

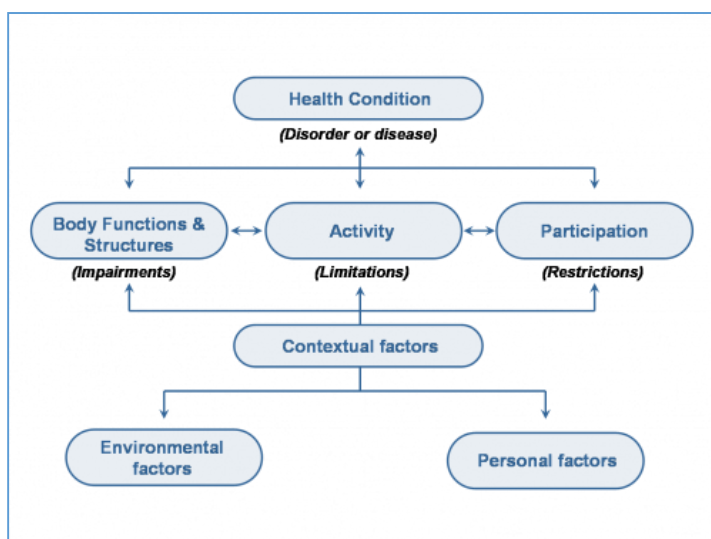


Fig 3: ICF Framework of disability

Source: Rehab-scales.org

### Definition of “Key Informant”

The term Key Informant has been used by a number of organisations and research bodies to refer to community based volunteers recruited based on their social knowledge and standing in their communities. In the KIM, we define KIs as community volunteers recruited to identify children with specific moderate or severe impairments or health conditions in their local communities.

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