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# Research Summary: The Key Informant Child Disability Project in Bangladesh and Pakistan

## Study Background

Door-to-door surveys are often used to identify children with disabilities in developing countries – either as beneficiaries for immediate interventions, or to estimate numbers (e.g. children with disabilities per thousand children) and plan services. These can be costly and time consuming, and there is often a lack of comparability between studies and methods/definitions used. In line with international recommendations to collect appropriate and comparable statistical data on disability, so as to enable governments and other stakeholders to formulate suitable policies and programs, investing in the development of cost effective and functional methods is imperative[a][b].



## Study Purpose

The Key Informant Method (KIM) has previously been tested by CBM, The London School of Hygiene and Tropical Medicine (LSHTM) and others, and found to be a valid, method for the identification of children with severe visual impairment and blindness in countries including Bangladesh, using community volunteers in the place of a (more costly) door-to-door survey.

The current study set out to expand this and test whether voluntary, community-level Key Informants (KIs) in three districts in Bangladesh and one in Pakistan could be trained to effectively identify children with moderate or severe physical impairments, sensory impairments (visual and hearing) or epilepsy, and if so whether this process could be used to assess prevalence[c] and plan appropriate referral services for children meeting these criteria. The study also undertook a large door-to-door survey in Bangladesh to compare estimates produced using the different methods. A door-to-door survey was not possible in Pakistan.
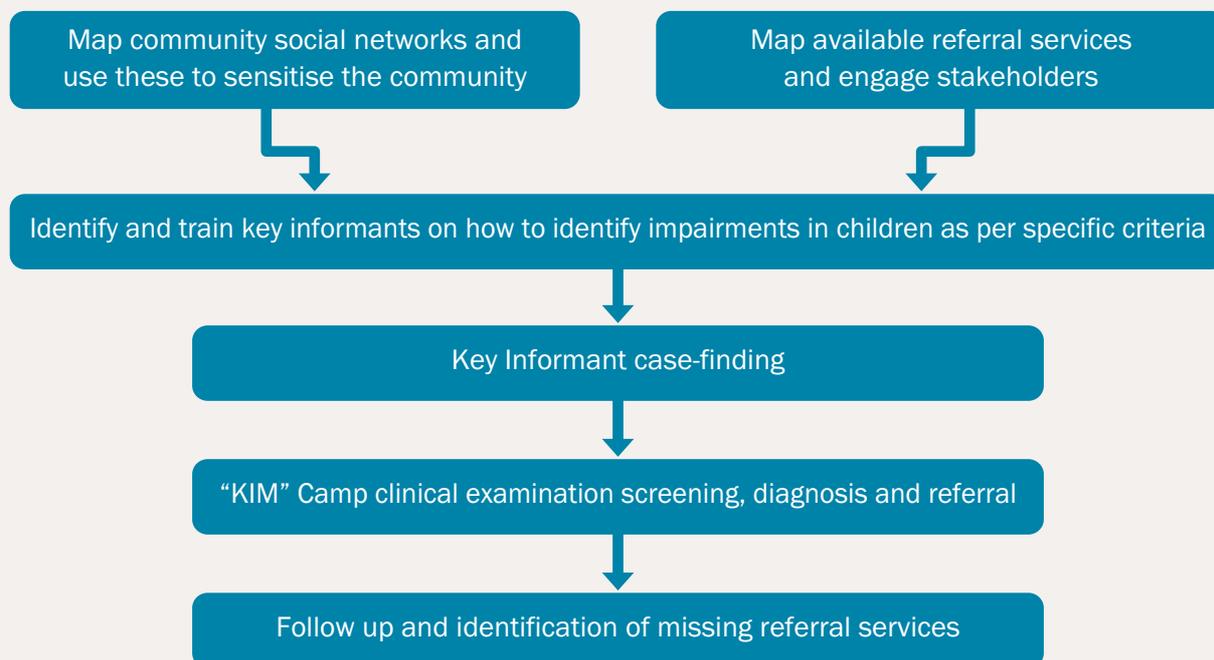
**Photo A:
Examination,
Bangladesh**

a   The United Nations Convention of the Rights of Persons with Disabilities and Optional Protocol (2008) is available at www.un.org/disabilities

b   The World Report on Disability (World Health Organization and The World Bank 2011) is available at www.who.int/disabilities/world_report/

c   Prevalence refers to the proportion of the total child population found to have the targeted conditions.

## Figure A: The Key Informant Method

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┌─────────────────────────────┐        ┌─────────────────────────────┐
│ Map community social        │        │ Map available referral      │
│ networks and use these to   │        │ services and engage         │
│ sensitise the community     │        │ stakeholders                │
└──────────────┬──────────────┘        └──────────────┬──────────────┘
               │                                       │
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                              ▼         ▼
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│ Identify and train key informants on how to identify impairments  │
│ in children as per specific criteria                              │
└────────────────────────────────┬─────────────────────────────────┘
                                 ▼
              ┌──────────────────────────────────────┐
              │ Key Informant case-finding           │
              └──────────────────┬───────────────────┘
                                 ▼
              ┌──────────────────────────────────────┐
              │ "KIM" Camp clinical examination      │
              │ screening, diagnosis and referral    │
              └──────────────────┬───────────────────┘
                                 ▼
              ┌──────────────────────────────────────┐
              │ Follow up and identification of      │
              │ missing referral services            │
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## Key Findings

1. KIM identified almost 100% of children with severe visual impairments, significant physical impairments and epilepsy in Bangladesh
2. KIM was less effective at identifying children with hearing impairments in Bangladesh
3. Key Informants in Pakistan identified approximately 75% of all children with targeted impairments and conditions, with more evidence needed[d]
4. Key Informants showed interest in maintaining a long-term role as community disability advocates (piloted Community Module in Bangladesh on further training, coaching and mentoring of Key Informants)
5. 57% of children with targeted impairments/ health conditions in Bangladesh, and 83% of those in Pakistan had never previously received rehabilitative support or services
6. KIM is a more cost effective method of identifying children with targeted impairments and health conditions than a door-to-door survey covering a population of the same size.
7. Promising findings from KIM in Bangladesh suggest the potential benefit of using KIM in other settings to identify children with targeted impairments and health conditions

## Study Direct Benefits

1. Training of over 1,500 community KIs in Bangladesh and 500 in Pakistan (approximately 1 KI per village across a defined population) using flip charts, specific messages about different impairments and health conditions, and general messages about disability
2. Identification and clinical screening of almost 4,000 children in Bangladesh and 1,500 in Pakistan by comprehensive medical team
3. Screening of additional 8,000 children in Bangladesh via door-to-door survey for comparison
4. Provision of free medical/rehabilitative intervention to 3,000 children in Bangladesh and Pakistan
5. Mapping of referral services available and gaps existing in three districts of Bangladesh and one in Pakistan
6. Development of Community Module to equip 300 Bangladesh KIs with further knowledge and capacity to link communities up with referral services and further sensitise communities
7. Parent Group Training for caregivers of children with Cerebral Palsy in Bangladesh (consequent project)

d   Security issues within Pakistan external to the project created substantial difficulties for the project's implementation and may have affected the outcomes. Therefore KIM requires further testing in this setting before it can be recommended as an appropriate methodology for the identification of children with specific impairments and health conditions in Pakistan.

## Table A: Bangladesh Study Findings

| Bangladesh Study Findings | | KIM (N-258,000) | | Door-to-Door Survey (N-8120) | |
|---|---|---|---|---|---|
| | | n (Study) | Prevalence per 1,000 Children | n (Study) | Prevalence per 1,000 Children |
| **Moderate/Severe Impairment Prevalence:** | Physical | 1,601 | 6.2 [5.9 – 6.5] | 65 | 8.0 [6.1 – 9.9] |
| | Bilateral Visual | 184 | 0.7 [0.6 – 0.8] | 4 | 0.5 [0.01 – 1.0] |
| | Bilateral Hearing | 86 | 0.3 [0.2 – 0.4] | 52 | 6.4 [4.7 – 8.1] |
| **Specific Health Condition Prevalence:** | Cerebral Palsy | 953 | 3.7 [3.5 – 3.9] | 21 | 2.6 [1.5 – 3.7] |
| | Epilepsy | 390 | 1.5 [1.4 – 1.7] | 18 | 2.2 [1.2 – 3.2] |
| | One or more of above | 2,334 | 9.0 [8.7 – 9.4] | 119 | 14.7 [12.0 – 17.3] |
| | One or more (ex. Hearing) | 1,937 | 7.5 [7.2 – 7.8] | 61 | 8.4 [6.4 – 10.4] |
| | Parent Report of Disability | 1,449 | 5.6 [5.3 – 5.9] | 25 | 3.1 [1.9 – 4.3] |

## Table B: Pakistan Study Findings

| Pakistan Study Findings | | n (Study) | Prevalence per 1,000 Children |
|---|---|---|---|
| **Moderate/Severe Impairment Prevalence:** | Physical | 759 | 3.9 [3.6 – 4.2] |
| | Bilateral Visual | 48 | 0.2 [0.2 – 0.3] |
| | Bilateral Hearing | 237 | 1.2 [1.1 – 1.4] |
| **Specific Health Condition Prevalence:** | Cerebral Palsy | 430 | 2.2 [2.0 – 2.4] |
| | Epilepsy | 153 | 0.8 [0.7 – 0.9] |
| | One or more of above | 1049 | 5.4 [6.1 – 5.7] |
| | Parent Report of Disability | 742 | 3.8 [3.5 – 4.1] |

*N: Child population screened using method*
*n (Study): Number of children identified using method*
*[ ]: 95% confidence interval of prevalence estimate*

## Study Indirect Benefits

1. Use of results to plan services for children with disabilities in Bangladesh and Pakistan
2. Use of results and findings by stakeholders to advocate for the inclusion of children with disabilities in Bangladesh in Pakistan
3. Use of results and findings by stakeholders to advocate for the inclusion of children with disabilities internationally
4. Learning for future KIMs (e.g. CBM/LSHTM KIM Malawi and CBM/LSHTM mini-KIM in Turkana, Kenya) to improve knowledge about children with disabilities locally and globally

## Key Recommendations

1. KIM can be used as a planning tool both to identify beneficiaries for a specific project and at the regional and national levels to estimate numbers and plan services for children with disabilities
2. KIM can be used in partnership with service providers to map referral pathways and estimate capacity and gaps within the system
3. KIM can be used to identify the extensive barriers to education and rehabilitative services that prevent children with disabilities from accessing them, and further work is needed in how to overcome these in partnership with stakeholders
4. Integration of CBR workers into the KIM, and of a KIM within the context of a CBR setting, could improve sustainability, capitalise on existing networks and maximise KI motivation
5. KIM can be further developed to become a holistic tool for evidence-based advocacy for CBM and other International NGOs through fully captioning the whole spectrum of child disability according to the International Classification of Functioning, Disability and Health (ICF).

# Comparison of Cost Effectiveness

Using the project costs in Bangladesh to screen a child population of 258,000 using KIM and 8,120 children via door-to-door survey, we can estimate what the costs would be to use either a KIM or a door-to-door survey to screen a total population of 1,000,000 (of which an estimated 413,000 are children). Comparing these costs shows that KIM costs approximately ten times less than a door-to-door survey to cover a total population of the same size.

### Table C: Comparison of Cost Effectiveness

| Bangladesh Numbers and Costs to Screen a Population of One Million Using Both Methods | | |
| --- | --- | --- |
| | **KIM** | **Household Survey** |
| Total Child Population Covered[e] | 413,000 | 413,000 |
| Total No. Children Examined | 6,198 | 413,000 |
| Total No. Children Identified | 3,890 | 7,074 |
| Total Cost per Child Covered | £0.57 | £5.76 |
| Total Cost per Child Diagnosed | £63.12 | £369.00 |
| Total Cost per Child Referred | £108.24 | £1,118.19 |
| *Excluding Treatment and Travel Costs for Children* | | |
| Total Cost per Child Covered | £0.37 | £4.84 |
| Total Cost per Child Diagnosed | £40.97 | £309.97 |
| Total Cost per Child Referred | £70.26 | £939.29 |
| **Total Cost per Million** | **£245,534** | **£2,610,224** |
| **Total Cost per Million Excluding Treatment and Travel Costs for Chidren** | **£159,370** | **£2,192,631** |

The Key Informant Child Disability Project in Bangladesh and Pakistan was a four year study by the International Centre for Evidence in Disability (ICED) at the LSHTM. The project was funded by CBM Germany and supported by CBM International in partnership with the Child Sight Foundation (CSF), Bangladesh and the Comprehensive Health and Education Forum (CHEF), Pakistan.

Credits: Prof. GVS Murthy and Ms. Islay Mactaggart, The Key Informant Child Disability Project in Bangladesh and Pakistan, ICED Research Report 2013.

A full copy of the Main Report is available from the ICED website: http://disability centre.lshtm.ac.uk

Opinions expressed are those of the authors. Neither the London School of Hygiene and Tropical Medicine, nor CBM, take responsibility of the view expressed herein.

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e "Total Cost per Child Covered" means the cost per child in a total population of 1,000,000.