International Centre for Evidence in Disability

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

# The Key Informant Child Disability Project in Bangladesh and Pakistan

## Main Report 2013

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**This report reflects the views of the authors. Neither the London School of Hygiene and Tropical Medicine, nor CBM International take responsibility of the views expressed herein.**

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# Survey Teams

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# Acronyms

| | |
|---|---|
| **AD:** | Assistive Device |
| **AED:** | Anti-Epileptic Drugs/Medication |
| **CBR:** | Community Based Rehabilitation |
| **CDD:** | Centre for Disability and Development |
| **CHDRP:** | Community Handicap and Disability Resource Person |
| **CHEF:** | Comprehensive Health and Education Forum |
| **CI:** | Confidence Interval |
| **CISD:** | Centre for Services and Information on Disability |
| **CM:** | Community Mobiliser |
| **CP:** | Cerebral Palsy |
| **CSF:** | Child Sight Foundation |
| **dB HL:** | Decibels Hearing Level |
| **ENT:** | Ear Nose and Throat |
| **FGD:** | Focus Group Discussions |
| **HDI:** | Human Development Index |
| **HI:** | Hearing Impairment |
| **ICED:** | International Centre for Evidence in Disability |
| **ICEH:** | International Centre for Eye Health |
| **ICF:** | International Classification of Functioning, Disability and Health |
| **INCLEN:** | International Clinical Epidemiology Network |
| **KI:** | Key Informant |
| **KIM:** | Key Informant Methodology |
| **KIT:** | KI-Trainer |
| **LHW:** | Lady Health Worker |
| **LMIC:** | Low and Middle Income Countries |
| **LSHTM:** | London School of Hygiene and Tropical Medicine |
| **MD:** | Muscular Dystrophy |
| **MSI:** | Muscular-skeletal Impairment |
| **NGO:** | Non-Governmental Organisation |
| **OAE:** | Otoacoustic Emission |
| **OR:** | Odds Ratio |
| **PedsQL™:** | Pediatric Quality of Life Instrument |
| **PI:** | Physical Impairment |
| **PTA:** | Pure Tone Audiometry |
| **PWD:** | People with disabilities |
| **SVI:** | Severe Visual Impairment |
| **ToR:** | Terms of Reference |
| **UNCRC:** | United Nations Convention on the Rights of the Child |
| **UNCRPD:** | United Nations Convention on the Rights of Persons with Disabilities |
| **UNDP:** | United Nations Development Program |
| **UNICEF:** | United Nations Children’s Fund |
| **VI:** | Visual Impairment |
| **WG:** | Washington Group |
| **WHO:** | World Health Organization |

# Executive Summary

## Study Background

Door-to-door surveys are often used to identify children with disabilities in developing countries – either as beneficiaries for an intervention, or so as to be able to estimate numbers 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 states and state parties to formulate suitable policies and programs, investing in the development of appropriate methods is imperative [1-2].

## Study Purpose

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

The current study set out to expand this and test whether voluntary, community-level Key Informants (KIs) could be trained to effectively identify children with moderate or severe physical impairments, sensory impairments (visual and hearing) or epilepsy in Bangadesh and Pakistan, and if so whether this process could be used to assess prevalence and plan appropriate referral services for children meeting these criteria.

## 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 did not identify all children with targeted impairments and conditions, with more evidence needed
4. 39% of school-aged children with targeted impairments/health conditions in Bangladesh, and 28% of those in Pakistan attended school compared with 84% of those without disabilities in Bangladesh and 52% in Pakistan.
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. Key Informants showed interest in maintaining a long-term role as community disability advocates (piloted Community Module in Bangladesh)

**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] |

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

**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 (Study): Number of children identified using method*
*[ ]: 95% confidence interval of prevalence estimate*

## Study Direct Benefits

1. Training of over 1,500 community KIs in Bangladesh and 500 in Pakistan (aprox 1 KI per village across a defined population) using flip charts, specific messages about different 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 diverse 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. Piloting of Community Module to equip 300 original Bangladesh KIs with further knowledge and capacity to link communities up with referral services
7. Parent Group Training for caregivers of children with Cerebral Palsy in Bangladesh

## 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 children with disabilities in Bangladesh in Pakistan
3. Use of results and findings by stakeholders to advocate for children with disabilities internationally
4. Learning for future KIMs (e.g. CBM/LSHTM KIM Malawi and CBM/LSHTM mini-KIM in Turkana)

## 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 service uptake that exist, and further work is needed in how to eliminate these in partnership with stakeholders
4. Integration of CBR workers into the KIM 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 ICF

# Introduction

## The Key Informant Methodology

The Key Informant Methodology has previously been validated by members of ICED as an effective way to identify children with Severe Visual Impairment (SVI) or blindness in Bangladesh [3]. KIM has since been utilized to identify childhood blindness in Iran and Malawi and was earlier used for childhood epilepsy in India [4-6]. The method relies on the training of community-level volunteers (Key Informants, or KIs) in the identification of children with targeted impairments or health conditions. KIs then list children meeting the criteria of their training who are screened at a Medical Screening Camp for functional limitations by a team of health professionals using objective clinical criteria[1]. Information is also collected on the child's clinical history, socio-economic status, participation in education and previous interaction with rehabilitative services.

## Study Purpose

To test whether voluntary, community-level Key Informants (KIs) can be trained to effectively identify children with moderate to severe physical impairments, sensory impairments or epilepsy, and if so whether this process can be used to assess prevalence of impairments and epilepsy in children and plan appropriate referral systems and services.

## Key Study Objectives

1. To develop, field test and refine the Key Informant method for identifying children with hearing impairment, epilepsy and physical impairments in addition to blindness
2. To ascertain whether KIM could provide estimates on prevalence and hence the magnitude of these impairments in children in Bangladesh and Pakistan
3. To determine if prevalence estimates generated using KIM were comparable with a population-based (household) survey in the same areas
4. To determine the causes of these impairments, and the proportion that could have been avoided
5. To develop a network of hospitals, agencies and organizations able to provide clinical services and rehabilitation for children with the different impairments
6. To develop a database of children with these impairments for the area of the study, which could be used for recruiting children to future studies
7. To investigate the impact of these impairments on affected children and their families

**Photo 1: Child with physical impairment, Bangladesh**


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[1] Refer to clinical criteria on page 14.

## Child Disability: Background

The United Nations Children's Fund (UNICEF) estimated in 2005 that 150 million children globally live with a disability, and that the majority of these are in low or middle income countries (LMICs), where they frequently lack access to primary and rehabilitative healthcare, education, and social inclusion [7]. Despite this large number, and estimates of childhood disability prevalence in LMICs ranging from 0.4% to 12.7%, very little accurate data on the magnitude of child disability exists [8-9]. The disparity and, in some situations, complete absence of accurate data on child disability has been linked by numerous authors to a combination of inaccurate or non-comparable screening tools and methodologies, culturally-specific understandings of disability, ambiguity surrounding terminology, and research apathy [10-12].

The lack of precise, robust disability data, alongside related information on the healthcare status and needs of children with disabilities is identified by the 2011 World Report on Disability as creating an enormous barrier to effective healthcare system design and decision making [2]. Providing key stakeholders within a given health system[2] with pertinent child disability information is a necessary, if not a sufficient, step in promoting access to healthcare and preventing impairment at the primary and rehabilitative levels. Moreover, given the established empirical cyclical link between poverty and disability in LMICs, it is equally imperative that health systems and stakeholders ensure not only availability of appropriate services, but financial and geographic accessibility of those services to individuals and communities in need [11, 13].

## Child Disability in Bangladesh

Bangladesh, with a current estimated population of 142,319,000, is ranked 146th out of 179 countries in the 2011 United Nations Development Program's Human Development Index (HDI) and has an under-5 mortality rate of 52/1,000 children [14-16]. Numerous conflicting figures for disability prevalence (all ages) in Bangladesh exist, ranging from 0.64 to 10% [17]. The 2004 World Bank situational analysis of disability in Bangladesh estimates a child disability prevalence in the country of 6% based on available estimates and figures [18]. The report also argues for the urgent need to establish accurate prevalence figures so as to facilitate early detection, plan appropriate rehabilitation strategies, and ensure strong referral networks specifically at the district level [18]. A national survey of disability in Bangladesh defines disability within the Bangladeshi context as a "complex form of deprivation", leading to persons with disabilities in the country maintaining low capability and self confidence within the country's physiological, social and cultural spheres [19]. Concerted and sustained activities to overcome this are clearly necessary so as to be able to provide the appropriate services to both adults and children with disabilities [20].

## Child Disability in Pakistan

The 2011 Pakistan Census Data has not yet been released, but data from the UNDP 2011 Human Development Report estimates the current country population as 176.7 million. The last Pakistan Census, in 1998, stated a disabled population of 2.54%, a figure that has been strongly criticised for its narrow, medical interpretation of severe, visible impairments in functioning [21-22]. Other figures estimated have ranged up to 10% [22]. The vast majority of children with disabilities in Pakistan are not in school, and those that are face stigmatization and discrimination from other students, teachers and community members that they pass en route to school [23]. For those enrolled in school, there is limited availability of Special Needs trained teachers, and accessibility of the built environment is minimal [23].

## Cultural Beliefs about Child Disability in Bangladesh and Pakistan

In both Bangladesh and Pakistan, prevailing attitudes towards disability are that it is "the will of God" or supernatural forces, either as a test or as punishment for sins previously committed [22, 24]. This, along with the perspective that people with disabilities

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[2] Defined by the World Health Organization (2000: xi) as "all the organizations, institutions and resources that are devoted to producing health actions".

create a “social burden”, leads to significant stigma in both countries, and in itself creates and strengthens barriers against inclusion, participation and uptake of rehabilitative services [23, 25].

## Education of Children with Disabilities in Bangladesh and Pakistan

Pakistan has a Gross Primary Enrolment Rate[3] of 80%, decreasing to 45%, 30% and 12% for mid-elementary, secondary and higher secondary Gross Enrolment Rates respectively [26]. Primary Enrolment Rates are not available for Bangladesh, but data from 2006 estimates over 4 million more boys enrolled in education than girls in Pakistan, and that only 4% of school-age children with disabilities in both Bangladesh and Pakistan attend school [22, 27].

In both countries, secular education is paralleled by the Madrassa education system. Madrassas. accounting for approximately 33% of Post-Primary education in Bangladesh and a similar percentage in Pakistan, teach both secular and religious curricula founded in religious belief [28-29]. Madrassas are traditionally independent of the state but in Bangladesh the vast majority receive public aid to fund their activities [28]. In Pakistan, Madrassas are registered as charitable corporate bodies and receive tax-exempt status from the Government [29].

Inclusive and adaptive education for children with additional learning needs are sparse in both Bangladesh and Pakistan. Many educational facilities are physically inaccessible for children with mobility impairments, whilst stigma and limited teacher training can form barriers for children with many types of impairment.

## Government Definition of Disability in Bangladesh

“ [A]ny person who, a. is physically crippled either congenitally or as result of disease or being a victim of accident, or due to improper or maltreatment or for any other reasons became physically incapacitated or mentally imbalanced, and b. as a result of such crippledness or mental impairedness, (i) has become incapacitated, either partially or fully; and (ii) is unable to lead a normal life.” [30]

## Government Definition of Disability in Pakistan

“A person with disabilities means a person who, on account of injury, disease or congenital deformity, is handicapped in undertaking any gainful profession or employment, and includes persons who are visually impaired, hearing impaired, and physically and mentally disabled.” [25]

## Disability Legislation/Policy in Bangladesh and Pakistan

Table 1 on the following page gives an overview of the major international and national legislation related to disability in Bangladesh and Pakistan. Both countries have ratified the relevant International Conventions and have undertaken National Plans on disability. Reporting on the efficacy of these plans pertain to a lack of resources (financial and human) to implement specific policies and plans in their entirety [23, 31].

**Photo 2: A young boy writes with his foot in Bangladesh**

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[3] Gross Primary Enrolment Rate is defined by the World Bank as “total is the total enrolment in primary education, regardless of age, expressed as a percentage of the population of official primary education age. GPER can exceed 100% due to the inclusion of over-aged and under-aged students because of early or late school entrance and grade repetition”.

### Table 1: Bangladesh and Pakistan Disability-Related Legislature

| | Legislative Area | Legislation/Committee | Position |
|---|---|---|---|
| Bangladesh | **International Convention** | United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) | Ratified by Bangladesh on 30th November 2007. Optional Protocol ratified 12th May 2008. |
| | | United Nations Convention on the Rights of the Child (UNCRC) | Ratified by Bangladesh 3rd August 1990 |
| | **National Plan** | National Action Plan on Disability 2006 | Includes appointment of focal disability person in each of 46 Government Ministries tasked with ensuring access to services by PWDs |
| | **Education** | | Anecdotal evidence of educational stipend that is only granted to small number of disabled students |
| | **Social Welfare** | National Coordinating Committee, Ministry of Social Welfare | Coordinating mechanism, established as part of 2001 Disability Welfare Act to oversee the development and implementation of disability policy. |
| | **Employment** | Persons with Disability Welfare Act (2001) | 10% employment quota for persons with disabilities in all cadre service (government) jobs |
| Pakistan | **International Convention** | United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) | Ratified by Pakistan on 5th July 2011 (Optional Protocol neither signed nor ratified) |
| | | United Nations Convention on the Rights of the Child (UNCRC) | Ratified by Pakistan 12th November 1990 |
| | **National Plan** | National Plan of Action 2006-2025 to implement the National Policy for Persons with Disabilities (2002) | Concessions include free medical treatment for PWDs, financial support and employment quota in public and private sector |
| | **Education** | National Plan of Action 2001-2015 based on Education for All (UNESCO, 1990) Jomtien Goals | Children with disabilities mentioned once in goal 4 of Jomtien Conference: “Expansion of early childhood care and developmental activities, including family and community interventions, especially for poor, disadvantaged and disabled children.” No specific strategy/ budget for achieving this outlined |
| | **Social Welfare** | National Coordination Committee, Ministry of Women’s Development, Social Welfare and Special Education | Responsible for policies on employment/ rehabilitation for persons with disabilities |
| | | National Council for Rehabilitation of Disabled Persons (NCRDP), Ministry of Women’s Development, Social Welfare and Special Education | Conducts disability surveys, provides vocational training and medical assistance |
| | **Employment** | Disabled Persons (Employment and Rehabilitation) Ordinance 1981 | Sets a quota of 2% for employment of persons with disabilities in public and private sector |

*Sources: [1, 18, 22, 30, 32]*

# Methodology

## Study Protocol

### Steering Group

A Steering Group was constituted to guide the study. Members of the Steering Group were:

| | |
|---|---|
| **N K Arora** | Executive Director, The Inclen Trust International |
| **Mike Davies** | Head of Program Development, CBM UK |
| **Allen Foster** | President, CBM International and Co-Director International Centre for Evidence in Disability (ICED) and International Centre for Eye Health (ICEH), London School of Hygiene and Tropical Medicine |
| **Clare Gilbert** | Co-Director ICEH, London School of Hygiene and Tropical Medicine |
| **Sally Hartley** | Professor of Community Based Rehabilitation, University of Sydney |
| **Hannah Kuper** | Co-Director ICED, London School of Hygiene and Tropical Medicine |
| **Chris Lavy** | Senior Clinical Research Fellow and Honorary Consultant in Orthopaedic Surgery, University of Oxford |
| **Sue Mackey (2008-2011)** | Research Fellow in Child Disability, London School of Hygiene and Tropical Medicine |
| **Islay Mactaggart (2011-2012)** | Research Assistant in Disability, London School of Hygiene and Tropical Medicine |
| **Mohammad Muhit** | Executive Director, Child Sight Foundation |
| **GVS Murthy** | Reader, ICEH/ICED, London School of Hygiene and Tropical Medicine |
| **Christiane Noe** | Research Manager, Knowledge, Training and Learning Department, CBM International |
| **Vikram Patel** | Professor of International Mental Health & Wellcome Trust Senior Research Fellow, London School of Hygiene and Tropical Medicine |
| **Babar Qureshi** | Executive Director, Comprehensive Health and Education Foundation (CHEF), Pakistan |
| **Andrew Smith** | Honorary Professor, ICEH/ICED, London School of Hygiene and Tropical Medicine |

Prior to conducting any fieldwork, a Steering Group meeting was held in London to:

1. Review and agree definitions for study inclusion criteria (including the severity and definition of impairments targeted), to be taught to Key Informants
2. Agree on the age group to focus on
3. Agree on a KI training Package
4. Agree on the methods and equipment needed for assessment by the examining team
5. Review and design the data recording forms for use by the examining team

The Steering Group continued to meet twice a year throughout the project lifetime to discuss updates and provide ongoing recommendations and expertise.

## Definitions and Variables

### Definition of Child:

The United Nations drew up a definition of the child so that all countries having ratified the International Convention of the Rights of the Child share the same reference, which is laid down in Article 1 of the Convention as a 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.

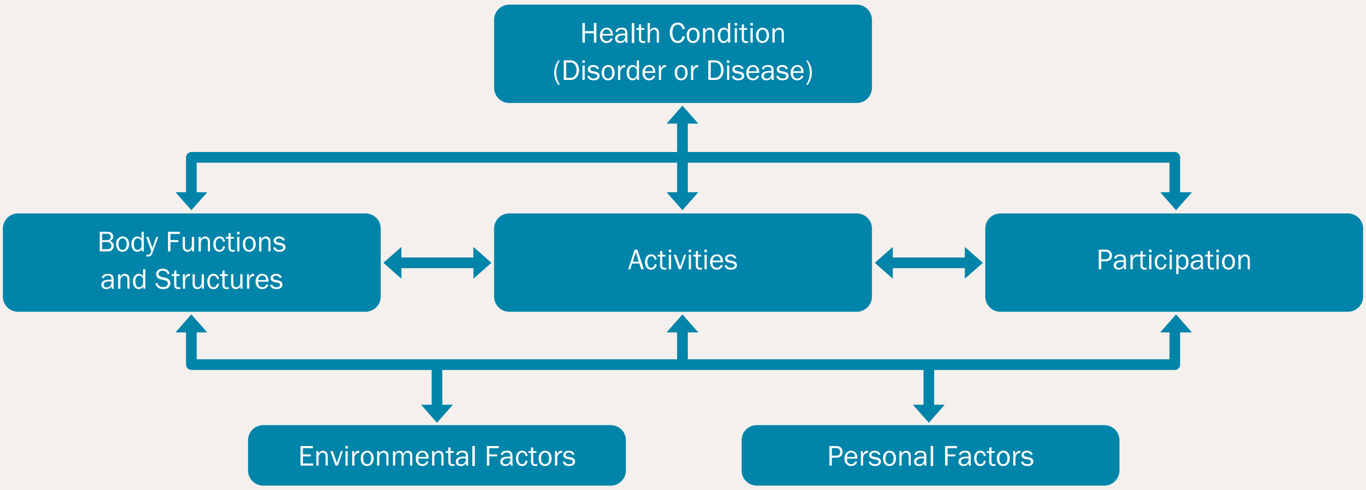
The same definition was adopted for this study.

### Definition of Disability:

Disability is understood within the project within the framework of the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) [33]. The ICF is an interactive bio-psycho-social model of disability that incorporates health conditions and functional impairments, activity limitations and participation restrictions (see Figure 1).

Within the broader scope of the ICF, the project focused on a sub-set of targeted health conditions and disorders/disease limiting body functions and structures. As outlined in Figure 1, this is only one component of disability. The project's more narrow target follows the KI Methodology's successful prior use in the identification of severe visual impairment or blindness in children in Bangladesh[4]. As in the previous study, strict inclusion and exclusion criteria were necessary to validate whether the methodology could be used to effectively identify children with other impairment types.

**Figure 1: The International Classification of Functioning, Disability and Health**



*Source: [31]*

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[4] SVI defined as presenting visual acuity <6/60 in better eye, blindness defined as presenting visual acuity <3/60 in better eye [34]. Muhit, M.A., et al., *Causes of Severe Visual Impairment and Blindness in Bangladesh: A Study of 1935 children*. British journal of ophthalmology, 2007. **91** (8): p. 1,000.

## Study Inclusion Criteria

All children aged 18 and younger resident in the targeted districts of Bangladesh and Pakistan were included in the study. Following their training, Key Informants listed all children in their villages that they believed matched the criteria targeted by the study[5]. These children were all then invited to attend KIM Screening Camps, alongside a smaller number of children that had not been listed by KIs, randomly selected from the village for comparison. Children listed by KIs are known in the study as "KI Listed", whilst children randomly selected for comparison are known as "Non KI Listed" children. Children with intellectual impairments and/or learning delays were not included in the study for two reasons. Firstly, the project team were unaware of any appropriate tools that can be utilised at the community-level to screen for intellectual impairment, and secondly the ethical implication of referral services not existing in Bangladesh.

The following criteria, based on WHO guidelines on moderate or worse impairment, were employed in the study in defining targeted moderate or worse physical or sensory impairments or epilepsy in children:

**Physical Impairment:** "Substantial" impairment of six months duration (or from birth if younger), affecting functions as per not being able to easily do one or more of the functions in the Washington Group Questions (see opposite).

**Visual Impairment:** Presenting Vision <6/60 in better eye if aged > 5 years and inability to follow a light source if <= 5 years of age.

**Hearing:** Presenting hearing of >30 decibels Hearing Level (dBHL) in both ears averaged at 0.5, 1, 2, and 4 kHz if >5 years and tested using Pure Tone Audiometry (PTA), failure of Otoacousitc Emission (OAE) test in both ears if <=5 , or strong clinical suspicion by ENT specialist if both PTA and OAE screening not possible.

**Epilepsy:** History of generalized tonic-clonic seizures within past three months.

A child is a STUDY POSITIVE if meeting one or more of the above criteria.

## The Washington Group Questions

The Washington Group on Disability Statistics was established by the United Nations to develop a tool, compatible with the ICF, for the collection of comparable data on disability globally. The Washington Group Short Set are a set of six questions that focus on key functioning domains or basic actions (seeing, hearing, walking, cognition, self-care and communication).

The questions have been shown to produce internationally comparable data that can be used to estimate disability prevalence, and each has four response categories of increasing severity of functioning limitation: (1) No difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do at all.

Several cut-off points can be used for measuring disability.

1. At least *Some difficulty* in at least *one* of the six domains
2. At least *A lot of difficulty* in at least *one* of the six domains
3. *Cannot do at all* in at least *one* of the six domains
4. At least *A lot of difficulty* in at least *one* of the six domains **or** at least *Some difficulty* in *two or more domains*

The present study uses the last threshold to identify parental perception of a moderate/severe physical or sensory impairment or epilepsy, as targeted in the study.

Washington
Group on
Disability
Statistics

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[5] Study target group – children < 18 yrs, with moderate to severe impairments + adapted Washington Group questions.

## Important Notes on Definitions

1. For the purposes of this report, “has disability” in the following Results chapter refers to children meeting the *inclusion criteria* on page 14 only. It does not include children presenting at the KIM Camps with mild impairments, unilateral sensory impairments or non-targeted impairments such as intellectual impairment and learning delay.

2. PTA readings of >30 dBHL signify moderate or worse hearing loss in children as per the WHO guidelines on hearing impairment that is “disabling” [35]. OAE readings (pass or failure) however, signify the presence of any hearing loss (including mild). In a number of cases it was impossible to take either clear PTA or OAE readings from the cohort due either to discharging ears or lack of response/ability to communicate to noise thresholds that were not related to hearing impairment. Cases in which the Ear Nose and Throat (ENT) specialist was *reasonably confident* that the child had a bilateral hearing impairment of presenting hearing of >30 dBHL, but was unable to confirm this via testing, are noted “Presumed Hearing Impaired” in the results section.

3. Usage of the Washington Group questions, as outlined in the column on the left, was adjusted due to the non-inclusion of intellectual impairment and learning delay in the project. Consequently, the question relating to cognition (“do you have difficulty concentrating or remembering) was excluded and the question relating to communication was adapted.

## Fieldwork Activities

Fieldwork in Bangladesh and Pakistan consisted of a phase-wise model (Figure 2) that emphasised community knowledge and built up local understanding of disability information and services. Further explanation of the stages of the model is provided in the text on the following page.

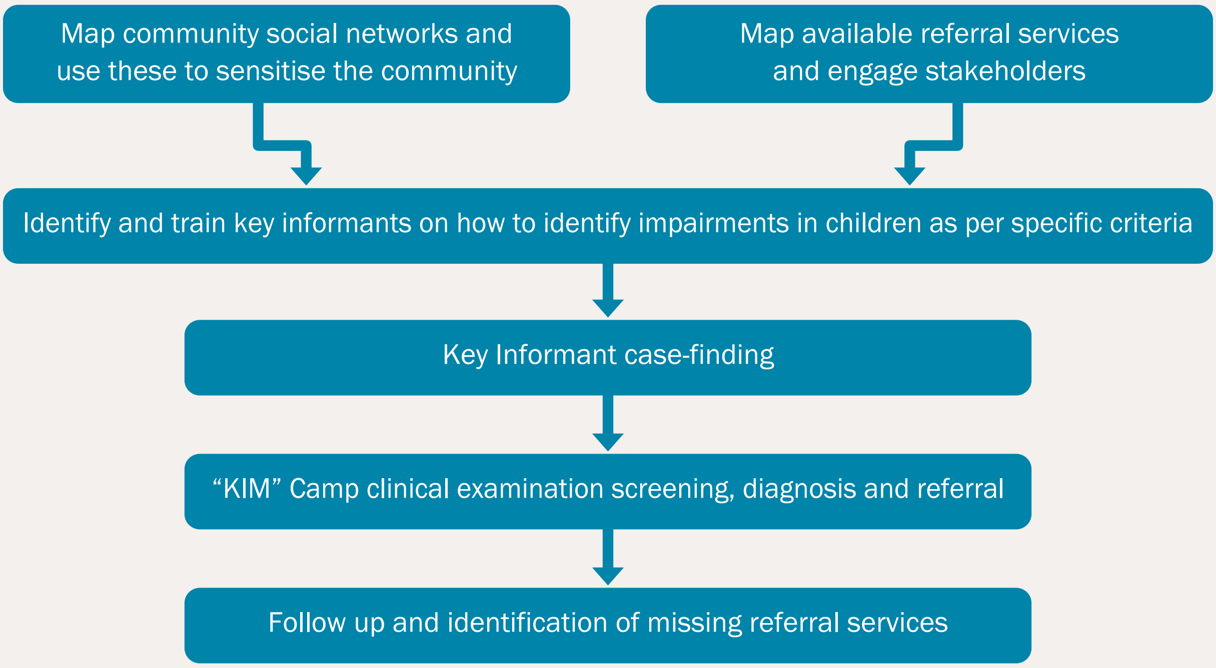
## Study Field Personnel

The study relied on a core team of mid-level field workers known as Community Mobilisers (CMs). CMs were recruited based on previous knowledge of disability and community activities and trained in:

1. Sensitization to disability issues
2. Liaison with community stakeholders (leaders, service providers, representatives)
3. Mapping of local services available for onward referral from KIM study
4. Communication of key health messages related to disability
5. Use of training materials (including flip chart) to train Key Informants
6. Identification of appropriate Key Informants and organisation of training programmes and support to Key Informants
7. Logistics and protocols of medical screening camps (including questionnaire schedules and organisation of camp procedures)
8. Counselling of parents and provision of follow up to referrals provided through study

CMs were allocated to the different sub districts where they first contacted district and local government departments concerned with social welfare, health and education for authorisation and sensitisation; and assistance in mapping of available services and recruitment of KIs from varied sources.

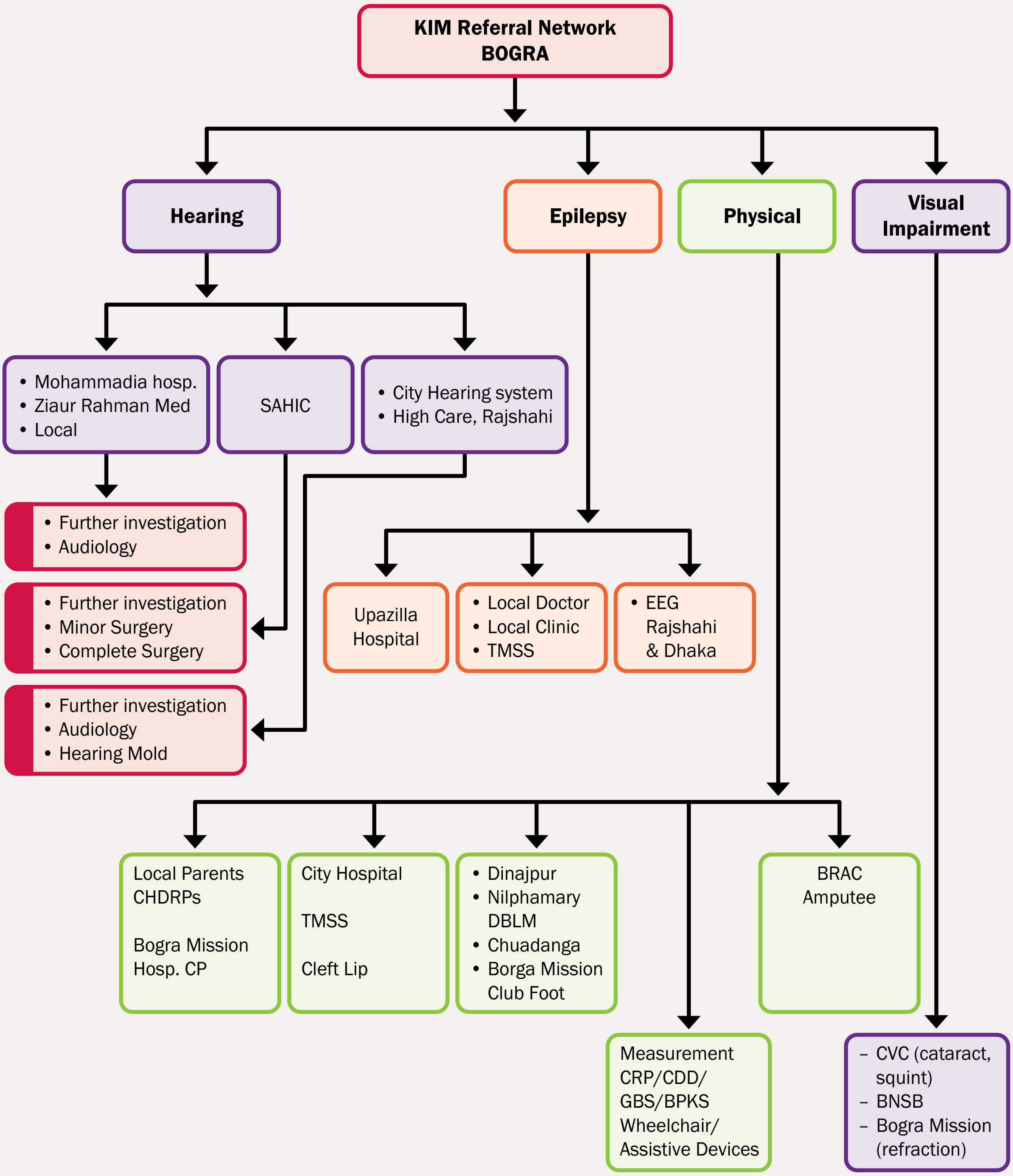
**Figure 2: The Key Informant Method**



## Referral Service Mapping

Mapping of referral services was completed prior to the implementation of the study in each district by the program managers from ICED, CSF and CHEF respectively, in collaboration with the project Community Mobilisers, local community stakeholders and service providers. The program managers met with administrators at referral units to solicit their support and only after their acceptance were the referral units included in the referral pathway. Referral pathways were sought for all targeted impairments, with pathways defined in each district/subdistrict as per Figure 3 below for Bogra, Bangladesh.

**Figure 3: Referral Service Mapping – Bogra, Bangladesh**



## Key Informant Identification and Training

KIs were predominantly recruited from amongst local government, non governmental organisations, village councils, teachers, imams and health workers. KI training and disability sensitisation workshops were conducted by the CMs using a standardised format and held in groups of approximately 20 KIs per session. The training focused on specially designed flipcharts in the local language, handout sheets containing information about targeted impairments and health conditions with visual illustrations, and a list of the key messages required for case finding.

KIs spread the messages within their normal working environment (schools, religious venues, community councils, public spaces etc.) and had 4-6 weeks to prepare a list of children found and their contact details. Usually parents self referred their children to the KIs and the community mobilisers followed up KIs in the villages to make arrangements for the medical assessment camps to ensure children and their parents were able to come. Approximately 100 KIs were trained per sub district (approximately 1 per village) and their participation was voluntary, without material reward throughout the process.

## Choice of Key Informants

Key Informants were identified using social mapping with community leaders. Individuals with influence and access to community members were prioritised and approached for training.

In Pakistan, the majority of Key Informants were Lady Health Workers (LHWs). The Pakistan health system employs over 100,000 LHWs, who are trained to deliver a range of maternal and child services at the community level including:

- Promotion of childhood immunisation
- Growth monitoring
- Family planning
- Health promotion

LHWs treat minor ailments and injuries, and refer serious cases to appropriate health care centres.

**Photo 3: Key Informant Training, Bangladesh**

Currently, LHWs are not trained in the prevention, early intervention or management of child disability [27].

Bangladesh does not have an equivalent community-based resource to the Lady Health Workers of Pakistan.

## Evolution of KIM Methodology

During the pilot in Bangladesh, Key Informants were trained to identify separate impairment groups of visual, hearing, physical impairment or epilepsy in separate sub districts with a 100,000 sampling frame. In the final 5th sub district a 'combined ' approach was used where KIs looked for all of the above impairments.

**Photo 4: A child with visual impairment, Bangladesh**

Table 2 outlines the sensitivity/specificity of the pilot. It was observed that the combined method worked better and was easier to adopt by the KIs and the communities, therefore this method was then used in the main study in Bangladesh and Pakistan. Within the Combined Method, the sampling frame was reduced to 50,000 per sub district so as to manage camp numbers (approximately 320 children examined per sub district in Natore).

The low specificity in the pilot reflects the fact that a large number of children who did not meet the study inclusion criteria (see page 14 for definitions) were referred to the screening camps. However it was observed that more than 80% of children attending the camp had an impairment or unmet health condition, not all of which met the inclusion criteria but all of which caused mild or (in the case of sensory impairments) unilateral functional limitations. Additionally, in the last two Natore sub districts (Baraigram and Gurudashpur) and all five Bogra sub districts, Community Mobilisers both conducted home visits to all children identified by KIs so as to screen for impairment before the camps, and sensitized communities to act as informal KIs. This limited the number of children referred to the KIM Camps that did not meet the inclusion criteria and was especially important in terms of children with hearing impairments that by definition are not visually identifiable. Table 3 outlines the full evolvement of the KIM methodology in Bangladesh. The KIM in Pakistan utilised the methodology as in Bogra throughout.

**Table 2: Sensitivity/Specificity of Pilot Methodology**

| Sensitivity/Specificity of Pilot Methodology | | | | |
|---|---|---|---|---|
| **Impairment Group (pilot)** | **Sensitivity** | **Specificity** | **Positive Predictive Value** | **Negative Predictive Value** |
| Visual | 100% | 69% | 65.8% | 100% |
| Hearing | 95.1% | 20% | 51.7% | 81.8% |
| Physical | 99.6% | 35% | 78% | 97.3% |
| Epilepsy | 97.1% | 71.4% | 79.3% | 96.8% |
| Combined Group | 99.8% | 24.4% | 77.6% | 98.0% |

**Table 3: KIM Bangladesh Methodology Evolution**

| KIM Bangladesh Methodology Evolution | | | |
|---|---|---|---|
| **District** | **Camp Type (Impairment)** | **Community Mobiliser Role:** | |
| | | **Validation** | **Cross Checks** |
| Sirajganj<br>5 camps | 1 x Physical (Ullahpara) | 5 x KI CM identified “norms” to validate KIM | |
| | 1 x Visual (Tarash) | | |
| | 1 x Hearing (Kazipur) | | |
| | 1 x Epilepsy (Shahjadpur) | | |
| | 1 x Combined (Kamarkhand) | | |
| Natore<br>5 camps | 5 x Combined | 5 x KI CM identified “norms” to validate KIM | 2 x CM checks on KI Lists and sensitising informal KI network |
| Bogra<br>5 camps | 5 x Combined | 5 x KI CM identified “norms” to validate KIM | 5 x CM checks on KI Lists and sensitising informal KI network |

Please note that the findings in this report all relate to the Combined KIM Methodology, in which KIs were simultaneously trained on identification of the four target impairments/conditions (physical impairment, visual impairment, hearing impairment and epilepsy). It does not include Pilot Data in Bangladesh collected in the four initial sub districts of Sirajganj, in which 586 children were listed by the KIs trained in identification of one impairment (or epilepsy) only. Please see Table 2 (page 19) for reference to the high Sensitivity and Specificity using the Combined approach, which was much better accepted by the KIs and the communities.

In Pakistan, the *Combined KIM* Methodology was used both in the pilot Tehsil (district) and three subsequent districts. All of this data is reported in the Results section.

## KIM Medical Screening Camps

Children identified by KIs were listed and names were provided to the CMs ready for registration at the medical assessment camps. Identified children who attended the assessment camp were examined by a team of specialists coming from Dhaka and Sialkot (in Bangladesh and Pakistan respectively) to confirm diagnosis and make appropriate referrals to rehabilitation services.

In addition, as a means of validating KIM, 50 children not listed by KIs from the KIM Camp assessment village location were randomly selected to attend the medical screening camps. This was intended to provide a measure of sensitivity and specificity of KIM in identifying children with impairments. Sensitivity refers to the proportion of screened children who were found to have a specific impairment among all those children who were labelled as having a targeted impairment or condition by the KI. On the other hand, specificity refers to the proportion of children who were correctly labelled as not having the targeted impairment among all those so labelled by the KI. Sensitivity therefore reflects correct detection rate of children with an impairment or targeted health condition by the KI, which means that children not detected by KI very rarely had the specific impairment.

A Household Survey (see page 24) was the main method of comparing the prevalence estimates generated by the KIM and was carried out from June 2009-2010 in the same 3 districts of Bangladesh (approximately 8,000 children examined).

## Medical Team

Most of the specialists in Bangladesh were enlisted from Dhaka to attend the assessment camps over 2 or 3 day periods. Similarly, the Pakistan team predominantly constituted specialists enlisted from the regional capital of Sialkot. They were trained on the methodology and completing the interactive data collection forms. The specialists performed examinations, provided diagnoses, identified causality, provided advice, gave information and referred children to appropriate services and treatments; subsidised by the project when necessary.

The full team attending each camp consisted of:

- 2 paediatricians
- 1 ophthalmologist
- 1 ENT doctor and 1 audiometrician
- 1 physiotherapist
- 1 local community disability worker (CHDRP)
- 1 counsellor

**Photo 5: KIM Camp, Pakistan**

## Referral Procedures

All children attending were assessed by the medical specialists who examined, diagnosed, advised, gave information, counseled and made referrals. Medical or rehabilitative referrals were offered to all children with unmet healthcare needs identified in the study, funded in their entirety by the project's donor, CBM, or provided free of cost by service providers. Referrals recommended by the medical team were recorded by each appropriate clinician under the last section 'M' on the Child Clinical Data form (Appendix 2). Families also held their own Child Record form that listed key information such as diagnosis, medication or recommended referrals e.g. further investigations, therapy, assistive devices, plasters or surgery. Where possible service provision was made through established or activated systems locally, or where necessary to further districts where more specialised treatment is available.

All families were seen by the project exit team who checked the forms, advised parents and dispensed any prescribed primary care medicines. The noted referrals were documented in the CSF/CHEF referral logs and it was explained to parents that where necessary, the CMs would contact them later to arrange support to take up the services (financial, logistical). Copies of this form were made for the CMs and the referrals coordinator, who subsequently entered them into the Referral log Excel database back at the project office.

During the pilot phase, direct medical treatment costs only were covered directly by the study, and parents had to make arrangements for all other logistics including transport, unless they were categorized as poor, resulting in low uptake. Therefore, for the remaining two districts in Bangladesh, and for the entire study in Pakistan, parents were specifically informed that all costs including travel would be covered by the project. Initially, costs of treatment were only included for the immediate medical management and in case of epilepsy for a one year period.

## Data Instruments

**Child Clinical Examination Form** (see Appendix 2)**:** The main data collection instrument, consisted of demographic details, income strata, parental perception of impairment/area of disability, activity limitations, access to education, rehabilitation, health seeking behaviour, clinical history and examination findings, followed by referral recommendations. Each medical practitioner filled in the relevant section, and a CM checked for completion before the child left the camp.

**KI Profile:** Details noted of location, occupation, age, gender, disability status, education level and assigned code number to enter on data forms.

**KI lists:** Contact details on each child's age, gender, presenting impairment and whether they had been seen by a doctor for the perceived impairment/ condition before or not.

**CM lists:** Similar details to KI list but used by CMs when randomly selecting the 50 children from the assessment camp village.

**PedsQL™:** The paediatric quality of life measure, extensively validated internationally for groups of children with different impairment [36]. A translation agreement was made with the authorized institute to undergo a full linguistic validation process in Bangladesh, according to the recommended guidelines.

**Follow Up Questionnaire:** administered to 267 families in Bangladesh only at one year post referral intervention. Questions cover areas such as; type of intervention, number of follow up treatments, barriers to uptake, participation levels , parental satisfaction etc.

## Project Extensions

In keeping with the learning experiences of the project, several additional elements evolved throughout the project lifetime:

### 1. Parent Group Training for Caregivers of Children with Cerebral Palsy in Bangladesh:

Children with Cerebral Palsy (CP), made up the greatest number within the cohort of children with disabilities identified, and CP is one of the most common causes of childhood disability in developing countries. 25.4% of children diagnosed with CP in the study presented with additional functional limitations or health conditions as part of their CP pathology, with epilepsy (13.6% of all children identified with CP) the most common.

Given the limited rehabilitative services for children with CP identified in the KIM study areas in Bangladesh, CBM, CSF and ICED established an independent Parent Group Training Project to develop and evaluate the acceptability of a model rehabilitation training programme for families of children with CP in rural Bangladesh.

This training programme was developed through action research following 14 parent groups over a 12 month period. It collected base-line qualitative and quantitative data on parents' and children's perceptions on their support needs and quality of life, and included case studies and regular feedback from staff, community mobilsers, and parents.

### 2. KI Community Module (Pilot) in Bangladesh

A second training module for Key Informants was developed and piloted in July 2012, to meet the needs of Key Informants for further training beyond identification, so as to become advocates for disability in their communities. KIs requested additional expertise in disability advocacy, information and awareness generation. The community module focused on building this capacity, training 12 KIs as "KI-Trainers" and supporting them in providing training for a further 300 of the original 1,500 KIs. Resources included the provision of resource booklets on rehabilitative services and disability information, and it is hoped that these KIs will continue to be supported by CSF beyond the project timeline.

**Photo 6: Parent Group training, Sirajgani, Bangladesh**

### 3. Additional 12 Months Anti-Epileptic Medication in Bangladesh and Pakistan

The budget for referrals originally included one year's supply of anti-epileptic medication (AEDs) for all children diagnosed with epilepsy in the study. The WHO guidelines report that 100% of children with epilepsy require a minimum 2 year course of AEDs, after which the medication can be stopped (gradually, over a period of approximately two months). Following two years medication, approximately 70% of children will remain permanently seizure-free, without needing to recommence medication. The remaining 30% are likely to need indefinitely continued AEDs to remain seizure-free. The 12 month supply of AEDs per child originally budgeted within KIM was therefore not sufficient to provide long-term seizure relief for KIM participants diagnosed with epilepsy in the study, all of whom require a minimum 2 year supply. An additional budget to purchase a second year's supply of epilepsy medication (including quarterly follow up with doctors) was therefore requested and approved by the donor for each child with epilepsy in the study. For those children needing indefinite supply, it is hoped that further consultations with local NGOs and caregivers will ensure this beyond the 2 year course.

## Data Collected

KIM in Bangladesh covered a total of 15 sub districts (5 per each of 3 districts) in rural Bangladesh, Rajshahi Division (approximately 200 miles north west Dhaka).

The complete data set consists of:

- Household Survey (n=8,141)
- Household Survey Revisit (n=600)
- KIM Camp Clinical Data Forms (n=4,911)
- KIM Camp PedsQL™ forms (n=2,133)
- One year post referral follow up Child Data forms (n=296)
- One year post referral follow up PedsQL™ forms (n=264)

In Pakistan, KIM was conducted in 4 upazillas (sub districts) of Sialkot district in the province of Punjab, each with 100,000 sampling frame (approximately 42% children). As a result of the political situation in the country, there was no Household Survey or one year follow up study in Pakistan. The complete data set consists of:

- KIM Camp Clinical Data Forms (n=1852)
- KIM Camp PedsQL™ forms

Map 1: Study Areas in Bangladesh and Pakistan

**Photo 7: A child waits to be screened in a KIM Camp, Pakistan**

## Household Survey Sample Size

In order to determine the sample size, an estimated prevalence of 16 per 1,000 for physical impairment, 1 per 1,000 for childhood blindness, 3 per 1,000 for hearing impairment and 3 per 1,000 children for epilepsy was considered. The final sample size was based on a prevalence of 16 per 1,000 for targeted impairments with 25% relative error (95% CI: 12/1,000 – 20/1,000). This yielded a required sample size of 3,780 children aged 0-18 years, if sample random sampling was used.

Assuming a design effect of 2.0 for cluster sampling design and a response rate of 85%, the sample size was increased to 8,900 children. Assuming 45.3% population is below <=18 years, this required a general population of size 19,650. If the clusters were composed of 450 persons or approximately 100 households, 42 clusters were needed. Therefore the number of clusters to be covered was rounded off to 45. This would result in 8,800 eligible children and adolescents being examined in the survey.

## Sampling Procedure

In the Household Survey, cluster random sampling was used. The clusters were of approximately equal size, with 200 children (0-18 years) being examined in each cluster. Bigger villages/wards were segmented to yield a total population of 450 which would yield 200 eligible children and adolescents (0-18 years). Villages/wards having smaller population sizes were clubbed together to yield the requisite number of children. A list of clusters was drawn up ranging in population between 400-500, which would yield between 180-225 children and adolescents. The cluster listing from the identified study areas represented the sampling frame.

## Ethical Approval

The population survey and KIM study on childhood disability were provided ethical clearance by the London School of Hygiene and Tropical Medicine, London, Bangladesh Medical Research Council and by the Ethics Committee of the Pakistan Institute of Community Ophthalmology for the respective countries. Informed consent was obtained from the parents of the children participating in the study. Parents and children were explained the purpose of the study in the local language, and only if they were willing to participate, their signature or thumb impression (illiterate populations) was obtained on the specially designed consent form. Subjects who refused to participate were not discriminated in any manner. All children needing the basic medical services were provided the same, irrespective of whether they were included or excluded from the survey. Primary care medications were dispensed to all those in need of them, and others who needed a referral or advanced diagnostic examination were referred to the appropriate places.

## Survey Data Collection

The Household Survey team consisted of a paediatrician, a paramedical assistant, two field enumerators and trained interviewers. The team underwent extensive training in disability awareness from the Program Managers and field team, as well as examination protocols developed for the study. Specific roles and responsibilities were communicated to all team members.

Each district was covered sequentially. Each cluster was completed in 3-4 days.

On entering a village, the local leadership was oriented to the purpose of the survey and a make-shift clinical examination station set up in the village.

After approval was obtained from the local community, the team of enumerators and interviewers first mapped the village and randomly identified the segment to be covered, based on the population in the villages. A random start was made from the centre of the identified segment by spinning a bottle and the team then moved from house to house sequentially until 200 children were covered. All children were provided a specific time for the clinical examination. At the clinical station, demographic information was re-verified and vision and hearing assessments were undertakane before the children were examined by the paediatrician. Children requiring primary care medication were provided the same while those needing referral were provided with onward referral cards. Children who did not come to the examination site after three attempts were then examined at home by the paediatrician.

## Data Management and Analysis

Data from both the KIM and the Household Survey was entered into a special Access software package developed for the project at Dhaka and CHEF office in Peshawar. All forms were checked for completeness in the field and again at the CSF office in Dhaka. Initial data cleaning was carried out at the Indian Institute of Public Health at Hyderabad and analysis was completed using Stata12.0 at ICED, LSHTM, London.

## Stakeholder Participation

A task force was set up in Bangladesh to help in implementing the study and for mapping referral networks in the country. The task force was scheduled to meet once in 6 months. The Terms of Reference (ToRs) of the Task Force were to:

- Provide technical advice on magnitude and management of childhood disability in Bangladesh.
- Participate in regular Task Force Meetings (at least twice a year).
- Help in networking with different agencies providing services for children with disabilities in Bangladesh.
- Assist in identifying service delivery institutions for support including long term care, surgery, therapy, inclusive education and assistive devices etc.
- Monitor the progress of the implementation of the Project.
- Advocate at the national and regional level.
- Identify mechanisms for integration of the Project results in the future implementation of programs for childhood disability in Bangladesh.

**Photo 8: Examination queue, KIM Camp, Bangladesh**

The members of the Task Force were drawn from disability organizations in Bangladesh, academics, CBM, CSF and ICEH. Sue Mackey was the first member secretary and Islay M. took over from her. Mr. Alam (Centre for Services and Information on Disability [CISD] ) and Mr. Noman Khan (Centre for Disability and Development [CDD] ) were elected as Co-Chairs.

The Task Force was originally given the task of networking with partners to take over the service delivery and support systems for children with moderate and severe impairments identified in the KIM study and to guide the conduct of the study. It was to meet at least twice a year in addition to the initial meeting and the dissemination. Though the meetings were regularly held, the participation of the members was not very enthusiastic and though it was suggested that they enter a joint proposal to follow up on the study, none of the task force members took an initiative in this regard. So though the Task Force was constituted with a lot of enthusiasm, it did not fulfil the initial promise.

Unfortunately, it was not possible to set up a Task Force in Pakistan. The team however ensured to create strong links with local stakeholders to guide the project's design and implementation.

## Training, Pilot Study and Inter-Observer Agreement

In Bangladesh, The survey team were trained at CDD, Sahik ENT Hospital, Dhaka Shishu Hospital and Sirajganj Medical College for the technical skills and disability orientation. The paramedical assistant was trained for 4 weeks on audiometry and vision assessment. A one week training was conducted by ICEH/ICED personnel in Dhaka where skills on enumeration, mapping, administration of instruments and survey logistics were provided to the team.

The pilot was conducted in 2 villages in Sirajganj district in June 2009. These villages were not part of the survey villages. The pilot was supervised by the ICEH/ICED team. All data was entered in the field and analyzed and feedback provided to the survey team. Data collection for the main study which covered 45 villages was conducted from July 2009 to July 2010 (11 months).

Monitoring visits to the survey villages were made at regular intervals by the CSF project manager and the research team from ICEH/ICED.

## Quality Assurance

Quality assurance procedures were implemented in the project from the planning stage to the data analysis stage. The processes adopted for quality assurance included:

1. Specific training inputs by the ICEH/ICED and CSF technical teams
2. Inter observer agreements during the pilot
3. A supervised pilot study in 2 villages
4. Developing a Manual of Operations, which was shared with all team members
5. Regular supervision by Principal/co Investigators at regular intervals
6. Pre coded data entry forms used to reduce data entry errors
7. Double data entry and verification
8. Dedicated data entry module with customized range and consistency checks
9. Data cleaning protocol followed rigorously

**Photo 9: Medical examination, KIM Camp, Pakistan**

# Results: KIM In Bangladesh

**Note: The following results relate to the Combined KIM Methodology, in which KIs were simultaneously trained on identification of all targeted impairments and health conditions. It does not include the Pilot Data collected in Bangladesh.**

**A child screens positive ("study positive") if meeting the following criteria: clinical diagnosis of moderate or worse bilateral visual or hearing impairment, moderate or worse physical impairment or epilepsy. Please refer back to page 14 for full study criteria and definitions.**

## Response Rates

**Figure 4: Distribution of Children Included in the KIM Study, Bangladesh**

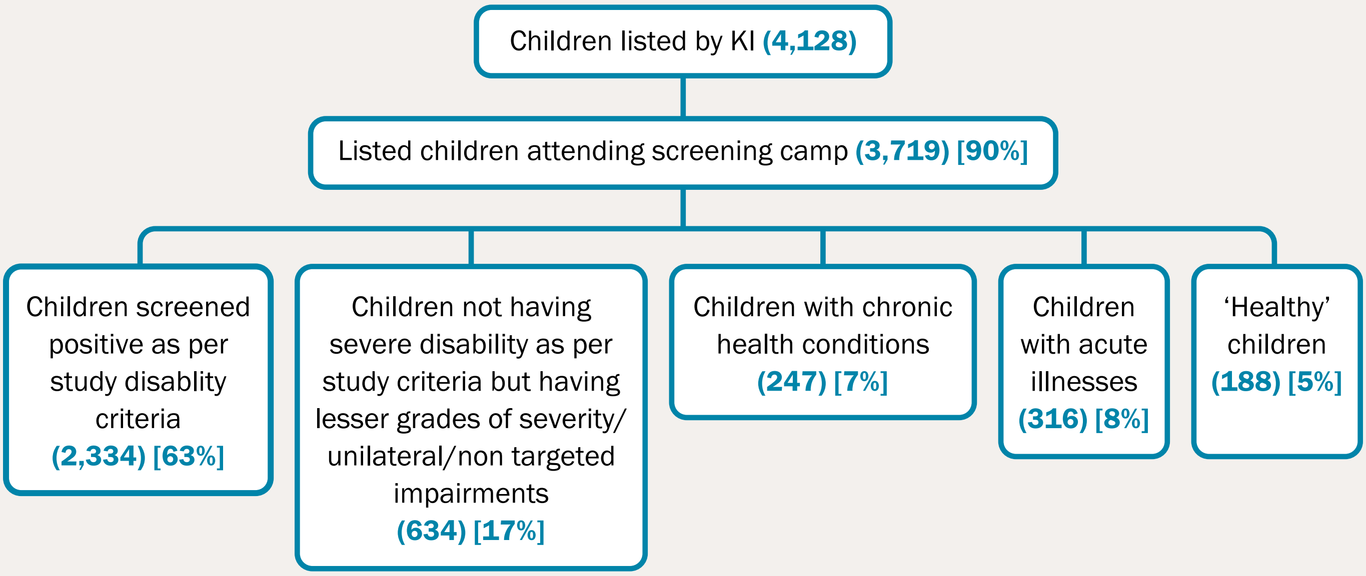
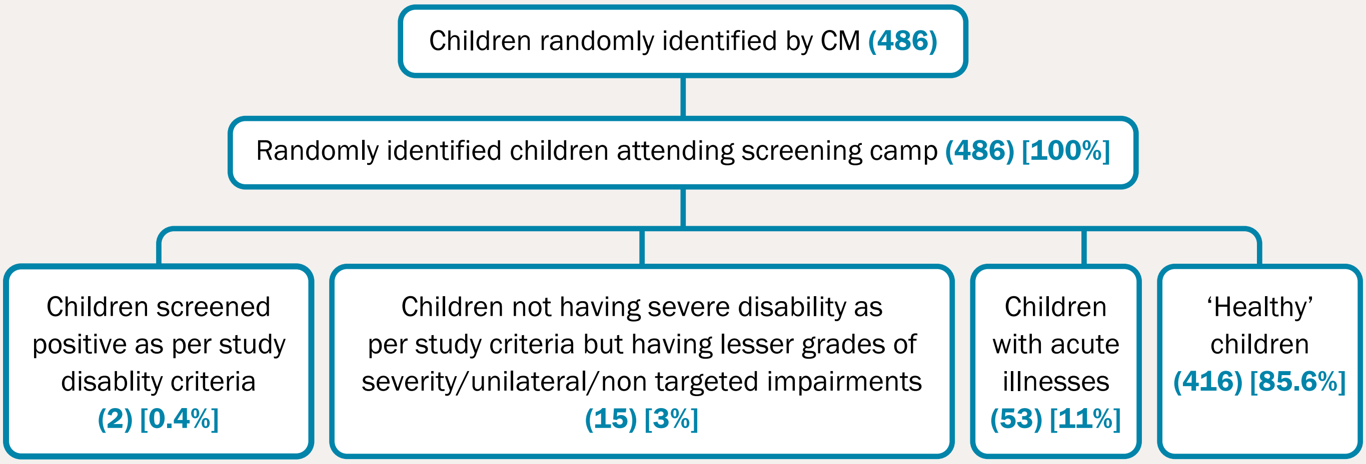


**Figure 5: Distribution of Children Examined from Normative Group (not Listed by KI), Bangladesh**



## Descriptives and Sensitivity/Specificity

### Table 4: Bangladesh – Demographic Characteristics of Children Covered in the KIM Study

| Cohort Descriptives – Age and Gender | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | Age (% Cohort) | | | | Total (n) | Total % |
| | | <=5 | 6-10 | 11-15 | 16-18 | | |
| KI Listed | Male | 16.1% | 19.7% | 12.5% | 8.1% | 2,096 | 56.4 |
| | Female | 11.6% | 14.5% | 11.1% | 6.5% | 1,623 | 43.6 |
| | **Total** | **27.7% (1,030)** | **34.1% (1,270)** | **23.5% (875)** | **14.6% (544)** | **3,719** | **100** |
| Non KI Listed | Male | 21.2% | 20.8% | 7.0% | 3.1% | 253 | 52.1 |
| | Female | 15.6% | 14.8% | 14.2% | 3.3% | 233 | 47.9 |
| | **Total** | **36.8% (179)** | **35.6% (173)** | **21.2% (103)** | **6.4% (31)** | **486** | **100** |

Table 4 outlines the age and gender characteristics of children listed by KIs and those screened for comparison (Non KI Listed). In both KI and Non KI Listed children, the gender ratio was almost equal (56.4% male in the KI Listed cohort and 52.1% male in the Non KI Listed cohort) and the majority of children (61.8% of KI Listed children and 72.4% of Non KI Listed children) were under the age of 11. The skewed age group ratio of children identified in the study is likely a consequence of older children no longer living in the family home.

3,719 children listed by Key Informants based on their training on the inclusion criteria for targeted moderate or worse physical visual, hearing impairments or epilepsy were screened at a medical screening camp alongside 486 children not listed by KIs, for comparison.

63% of the children listed by KIs screened positive at the medical screening camps as per the criteria, meaning that the remaining 37% of children that they listed did not (Table 5). Amongst those children screened for comparison (Non KI Listed), less than 1% screened positive, meaning that KIs identified 99.91% of all children with targeted moderate or worse impairments or epilepsy in their villages, as per their training.

Based on these classifications (screen positive or screen negative for study inclusion criteria by clinical examination), the sensitivity and specificity of the method was calculated (Table 6). Sensitivity was very high (KIs were correctly able to identify 99.91% of all children with targeted impairments), whilst specificity was low (KIs misidentified 25% of non-targeted children as matching the criteria). This means that the KIM is effective at identifying almost all children with moderate or worse physical or sensory (visual or hearing) impairments or epilepsy, but that a number of “false positives” who do not meet the study criteria are also picked up by KIs.

### Table 5: Bangladesh – Number of Children Screened by KI

| Cohort Descriptives – Study Positives | | | |
|---|---|---|---|
| **Group** | **Screen Positive for Moderate/ Severe Impairment or Epilepsy** | **Screen Negative for Moderate/ Severe Impairment or Epilepsy** | **Total** |
| KI Listed | 63% (2,334) | 37% (1,385) | 3,719 |
| Non KI Listed | 0.4% (2) | 99.6% (484) | 486 |
| **Total** | **2,336** | **1,869** | **4,205** |

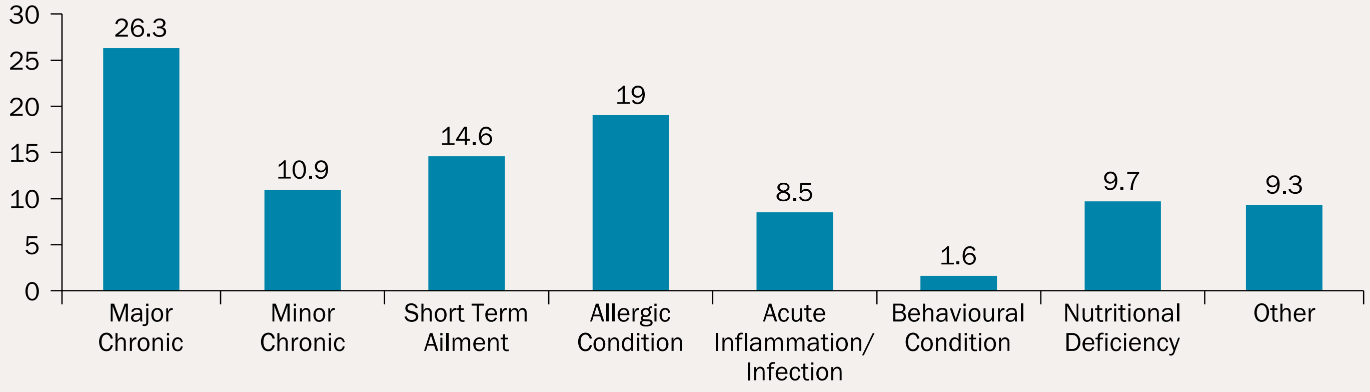
### Table 6: Bangladesh – Validity of the Combined Method

| Cohort Descriptives – Sensitivity/Specificity | |
|---|---|
| Sensitivity (%) | 99.91 |
| Specificity (%) | 25.90 |
| Positive Predictive Value (%) | 62.76 |
| Negative Predictive Value (%) | 99.59 |
| Correctly Classified (%) | 67.02 |

As discussed on page 8, the primary objective of this study was to validate whether KIM could be used to target specific impairments and health conditions, leading to strict inclusion/exclusion criteria. These criteria do not include mild impairments, unilateral or non-targeted impairments (such as intellectual impairments). Once KI Listed children with any of the above are included, total children screening positive for impairment increases to 2,930, Positive Predictive Value (percentage of children identified by KIs screening positive for targeted impairments/ epilepsy) increases to 78.78% and specificity increases to 38.1%

A number of children were brought to the camp with non-disabling morbidities. Figure 6 shows the distribution of these children (n=247).

**Figure 6: Bangladesh – Distribution of Other Co-Morbidities in Children Screened at KIM Camps (% of Children with Non-Disabling Morbidities)**



## Prevalence

Since 90% of the children identified by KI attended the KIM screening camps and because the sensitivity was high, a proxy prevalence proportion (the number of children per thousand children with a given impairment/ health condition) could be calculated based on the KIM. This is outlined in Table 7 (page 30), which outlines the prevalence per 1,000 children, per million total population and nationally amongst children, of the targeted impairment and health condition criteria. Note that this refers only to children meeting the inclusion criteria (i.e. moderate or worse physical or sensory impairment, or epilepsy, as per page 14) and not all children with disabilities.

### Table 7: Bangladesh – Prevalence and National Magnitude of Targeted Impairments/Health Conditions

| **Child Disability Prevalence – Clinical Screening** | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | **n (Study)** | **Prev/ 1,000 Children**[6] | **95% CI**[7] | | **Prev/ Million Total Population** | **95% CI** | | **National Magnitude (Child)**[8] |
| Moderate or worse Impairment | Physical | 1,601 | 6.2 | 5.9 | 6.5 | 2,563 | 2,438 | 2,688 | 397,240 |
| | Visual | 184 | 0.7 | 0.6 | 0.8 | 295 | 252 | 337 | 45,654 |
| | Hearing (presumed)[i] | 513 | 2.0 | 1.8 | 2.2 | 821 | 750 | 892 | 127,286 |
| | Hearing (confirmed) | 86 | 0.3 | 0.3 | 0.4 | 138 | 109 | 167 | 21,338 |
| Health Condition | Epilepsy | 390 | 1.5 | 1.4 | 1.7 | 624 | 562 | 686 | 96,767 |
| | CP | 953 | 3.7 | 3.5 | 3.9 | 1,526 | 1,429 | 1,622 | 236,459 |
| Study Positives (One or more of above) | | 2,334 | 9.0 | 8.7 | 9.4 | 3,736 | 3,585 | 3,887 | 579,112 |

[i] Hearing (presumed) includes children for whom the ENT specialist noted strong clinical suspicion of moderate or worse hearing impairment but for whom testing was not possible. Hearing (confirmed) denotes only those children for whom moderate or worse hearing impairment was confirmed via PTA (age >=5) or OAE (age<5).

## Washington Group Parental Report on Disability Prevalence (5 Questions)

2,147 (8.3 per 1,000) children in the study screened positive for disability as per the Washington Group (WG) Questions[9].

### Table 8: Bangladesh – Reported Degree of Difficulty Using WG Criteria

| **Washington Group Question Core Domain Limitations (% Study Positives)** | | | | |
|---|---|---|---|---|
| **Core Domains** | **No difficulty** | **At least some difficulty** | **At least a lot of difficulty** | **Unable to do it at all** |
| Vision | 90.2 | 2.7 | 3.6 | 3.5 |
| Hearing | 74.1 | 5.8 | 6.8 | 13.3 |
| Mobility | 49.3 | 11.9 | 16.4 | 22.4 |
| Communication | 51.4 | 7.8 | 11.3 | 29.5 |
| Self Care | 55 | 10.2 | 10.5 | 24.3 |

Table 8 outlines the percentage of Study Positives whose parents responded that they had some difficulty, a lot of difficulty or an inability at all in performing each of the five core functioning domains. Largest proportions of children were reported to have the most severe limitation (unable to do at all) in four of the domains (hearing, mobility, communication and self care), suggesting that there were greater numbers of children with severe limitation than mild or moderate limitations in the cohort.

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[6] Prevalence estimated using UNICEF 2012 on total population of sample area est. 600,000. Child popn ~ 41.3% total popn [37]. UNICEF, *Bangladesh Country Brief*. 2005.

[7] National Magnitude taken from census total population est. 142,319,000.

[8] Assumes validity of method (see page 60 for validation).

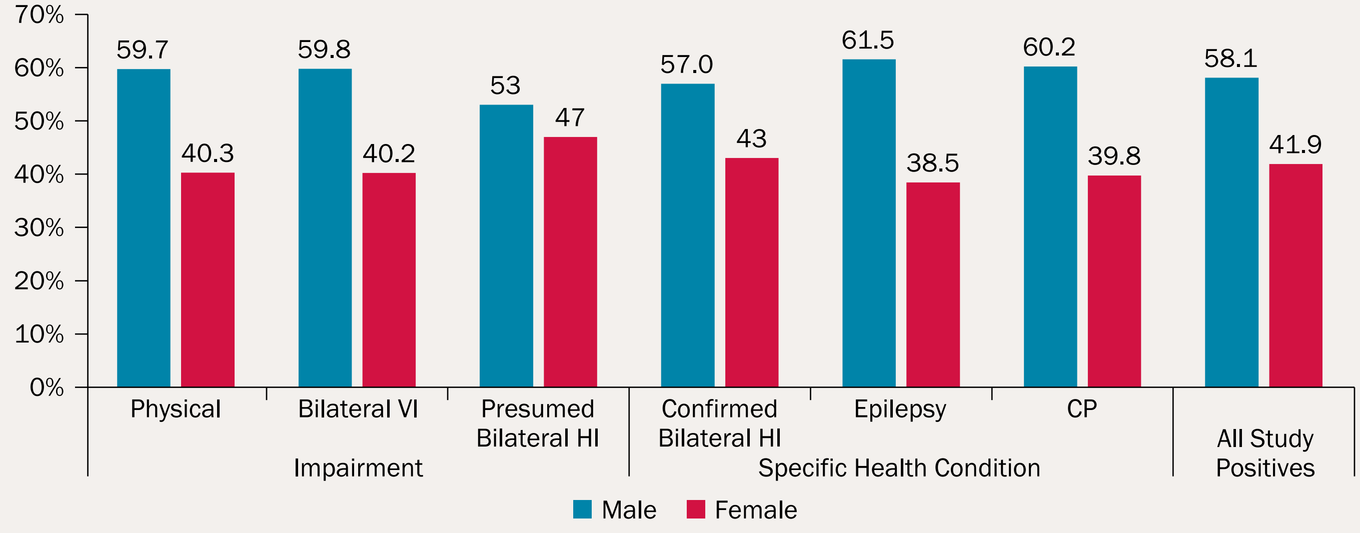
[9] Refer to page 14 for WG criteria.

### Table 9: Bangladesh – Concordance Between WG Criteria and Clinical Diagnosis

| Concordance between WG and Clinical Diagnosis (%) | | | | |
|---|---|---|---|---|
| | | **Clinical Diagnosis** | | |
| | | **Visual Impairment** | **Hearing Impairment** | **Physical Impairment** |
| Washington Group Parent Report Domain | Vision | **71.7** | 5.7 | 7.1 |
| | Hearing | 12.5 | **81.9** | 14.4 |
| | Mobility | 32.1 | 17.7 | **70.6** |
| | Communication | 27.7 | **73.3** | 49.3 |
| | Self Care | 45.7 | 23.8 | **57.5** |
| Screen Positive for Disability[10] | | 77.2 | 84.4 | 74.0 |

Table 9 shows concordance between specific core domains and clinically diagnosed moderate or worse impairments. The numbers signify the percent of children with each clinically diagnosed targeted physical or sensory impairment reported to have either some problem, a lot of problem or an inability to carry out each of the core function domains. Numbers in bold signify the concordance between each clinically diagnosed impairment type and the related functional domain. The highest concordance between diagnosed impairment and functional limitation was for hearing impairment (81.9% of children screening positive for moderate or worse hearing impairments were reported to have at least some problem in hearing by their caregivers), whilst 57.5% of children with diagnosed moderate or worse physical impairments were reported to have difficulties with self care.

**Figure 7: Bangladesh – Demographic Characteristics of Children Attending KIM Camps – Child Gender (% Study Positives)**



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[10] As per the Washington Group definition of at least *A lot of difficulty* in at least *one* of the six domains **or** at least *Some difficulty* in *two or more domains*.

## Demographic Characteristics of Children Attending KIM Camps

Figure 7 (previous page) shows the gender of all children screening positive for the targeted moderate or worse sensory or physical impairments, or epilepsy. Gender ratios were most pronounced amongst children with epilepsy, whilst more male children were diagnosed than female children across the spectrum of targeted impairments and conditions (58.1% male across all Study Positives).

Figures 8, 9 and 10 provide further demographic data on the cohort of children meeting the study inclusion criteria.

**Figure 8: Bangladesh – Demographic Characteristics of Children Attending KIM Camps – Age Group (%)**

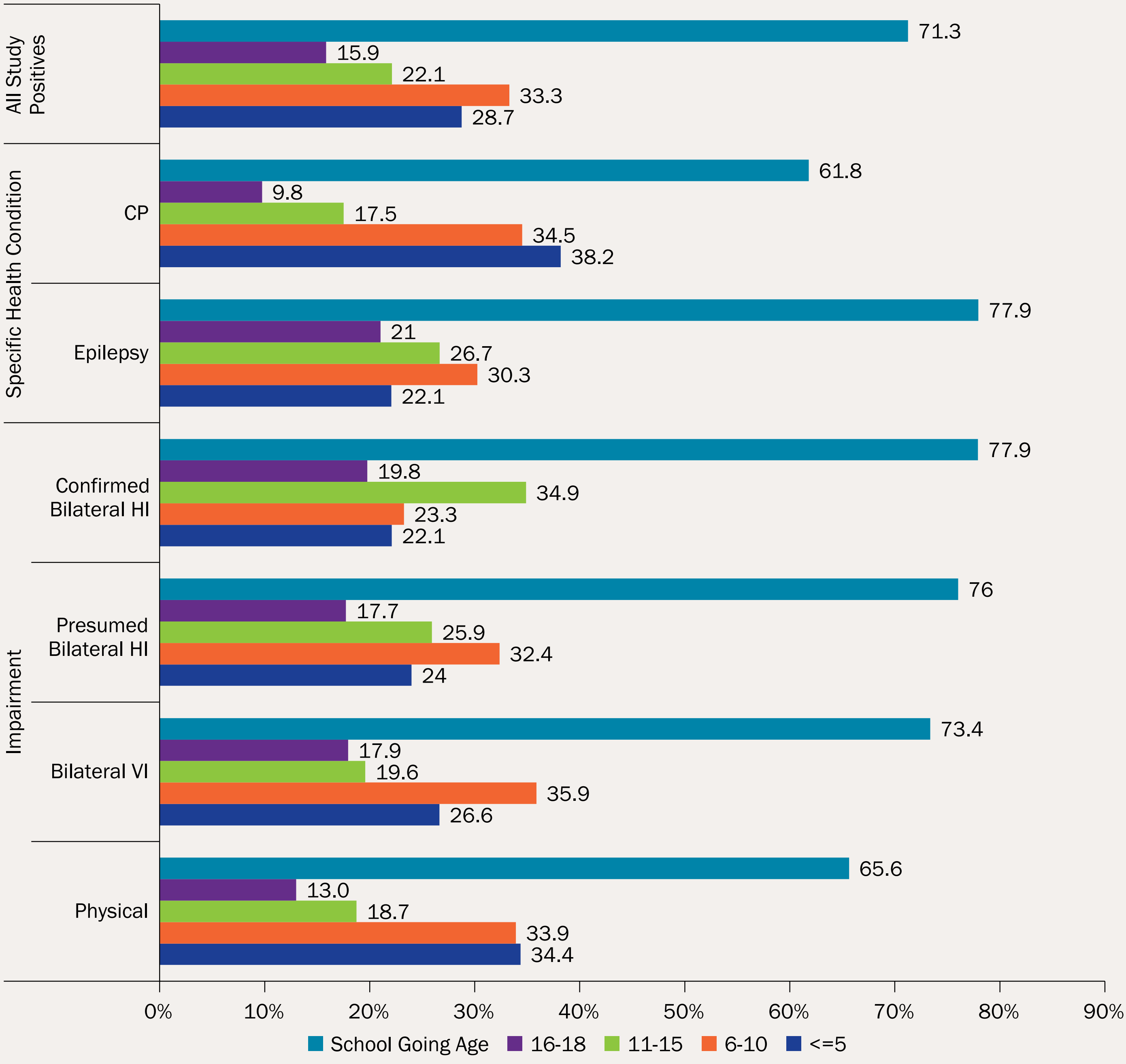
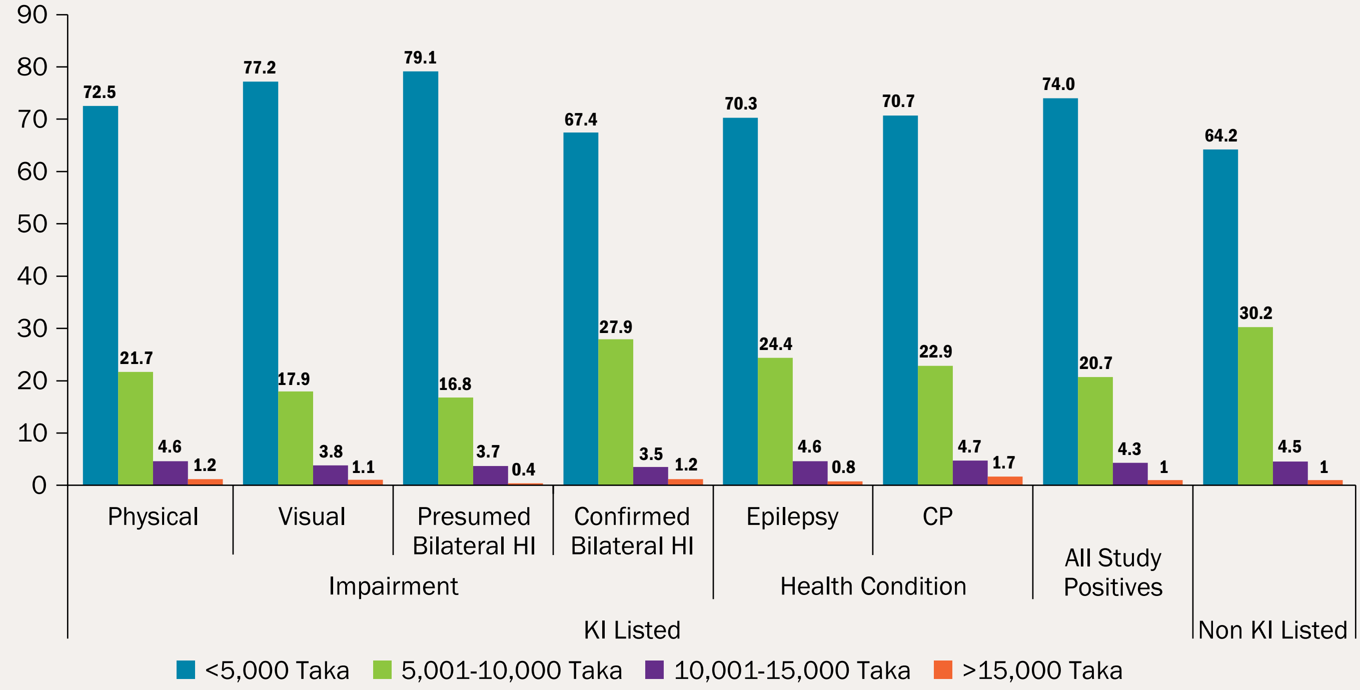


**Figure 9: Bangladesh – Demographic Characteristics of Children Attending KIM Camps**

**Figure 10: Bangladesh – Demographic Characteristics of Children Attending KIM Camps – Monthly Family Income (% Cohort)**



The vast majority (71.3% of all Study Positives) were of school-going age, with the largest proportion (33.3%) aged 6-10 and the lowest (15.9%) aged 16-18. This may be for many reasons, including that perhaps adolescents have already left the family home or because children with the most severe impairments do not survive to adolescence. Parental literacy amongst both children screening positive for the targeted impairments/health conditions and Non KI Listed children in the study was comparable. The majority of fathers of children with targeted impairments/health conditions and those of Non KI Listed children were illiterate (31.7% and 31.9% respectively). The majority of mothers of Study Positives and of Non KI Listed children were able to read and write (31.7 and 27.0 respectively).

A large majority (74.0% and 64.2% respectively) of both the study positive cohort and the cohort of Non KI Listed children reported being in the lowest band of monthly family income (<5,000 Takas/month[11]). 1% of both the study positive cohort and the cohort of children not listed by KIs reported being in the highest income bracket of >15,000 Takas/month.

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[11] 5,000 Takas is approximately equivalent to €47 or £50.

Multiple impairments among examined children were relatively common. 13% of all children meeting the study criteria had multiple targeted impairments or health conditions, predominantly (78% of those with multiple impairments) linked to Cerebral Palsy pathology (Tables 10 and 11).

### Table 10: Bangladesh – Cerebral Palsy Pathology

| CP Pathology | | |
|---|---|---|
| **Cerebral Palsy (CP) Pathology** | **n (Study)** | **% Children with CP** |
| CP– no other presentations | 711 | 74.6 |
| CP & Epilepsy | 130 | 13.6 |
| CP & Bilateral Hearing Impairment (HI) | 53 | 5.6 |
| CP & Bilateral Visual Impairment (VI) | 23 | 2.4 |
| CP & Epilepsy & Bilateral HI | 17 | 1.8 |
| CP & Epilepsy & Bilateral VI | 10 | 1.0 |
| CP & Bilateral HI & Bilateral VI | 7 | 0.7 |
| CP & Epilepsy & Bilateral HI & Bilateral VI | 2 | 0.2 |
| **Total** | **953** | **100** |

### Table 11: Bangladesh – Multiple Impairments/ Conditions Pathology

| Multiple Impairments/Conditions Pathology | | |
|---|---|---|
| **(Excludes children with Cerebral Palsy)** | **n (Study)** | **% of Study Positives** |
| Epilepsy with Bilateral HI | 7 | 0.3 |
| Epilepsy with Bilateral VI | 2 | 0.1 |
| Physical with Epilepsy | 17 | 0.7 |
| Physical with Epilepsy and Bilateral HI | 2 | 0.1 |
| Physical with Epilepsy, Bilateral VI and Bilateral HI | 1 | 0.04 |
| Physical with Bilateral HI | 23 | 1.0 |
| Physical with Bilateral VI | 14 | 0.6 |
| Bilateral VI with Bilateral HI | 4 | 0.2 |
| **Total** | **70** | **3.04** |

## Physical Impairment

Physical impairments were the most commonly observed impairments amongst the examined children, with 69% of all Study Positives diagnosed with a moderate or worse physical impairment significantly affecting functioning. Table 12 outlines the demographics of the cohort, which was predominantly male (59.7%).

### Table 12: Physical Impairment Demographic Characteristics

**Physical Impairment (PI) Demographic Characteristics**

| | **<=5** | **6-10** | **11-15** | **16-18** | **Total** |
|---|---|---|---|---|---|
| Male | 338 | 329 | 171 | 118 | 956 |
| Female | 212 | 214 | 129 | 90 | 645 |
| **Total** | **550** | **543** | **300** | **208** | **1,601 (100%)** |

### Table 13: Physical Impairment Prevalence

**Physical Impairments – Prevalence**

| **Health Condition**[12] | **n (Study)** | **Prev/ 1,000 Children** | **Prev/ Million Population** |
|---|---|---|---|
| Cerebral Palsy | 953 | 3.69 | 1,526 |
| Club Foot | 144 | 0.56 | 231 |
| Other Type Congenital | 118 | 0.46 | 189 |
| Muscular Dystrophy | 110 | 0.43 | 176 |
| Cleft Lip/Palate | 107 | 0.41 | 171 |
| Genetic | 85 | 0.33 | 136 |
| Trauma/Burn | 81 | 0.31 | 130 |
| Hydrocephalus | 39 | 0.15 | 62 |
| Polio | 28 | 0.11 | 45 |
| Spina Bifida | 14 | 0.05 | 22 |
| Amputee | 12 | 0.05 | 19 |
| Spinal Cord Injury | 10 | 0.04 | 16 |
| Rickets | 10 | 0.04 | 16 |
| Others | 234 | 0.91 | 375 |

Within the group with moderate or worse physical impairments, Cerebral Palsy was the single most common underlying health condition/cause (see Table 13 for prevalence estimations). Cerebral Palsy, a group of movement and posture disorders as a consequence of defect or lesions to the brain, can be caused prenatally, peri-natally or pos-tnatally and is particularly prevalent in developing countries due to the high incidence of conditions such as meningitis, septicaemia and malaria [39].

Figure 11 (following page) illuminates the gender ratios of the most common physical impairments, highlighting the significantly larger proportion of male Study Positives than female. This is most pronounced in Muscular Dystrophy (MD) diagnoses and least pronounced in diagnoses of other (unspecified) congenital conditions significantly affecting physical functioning.

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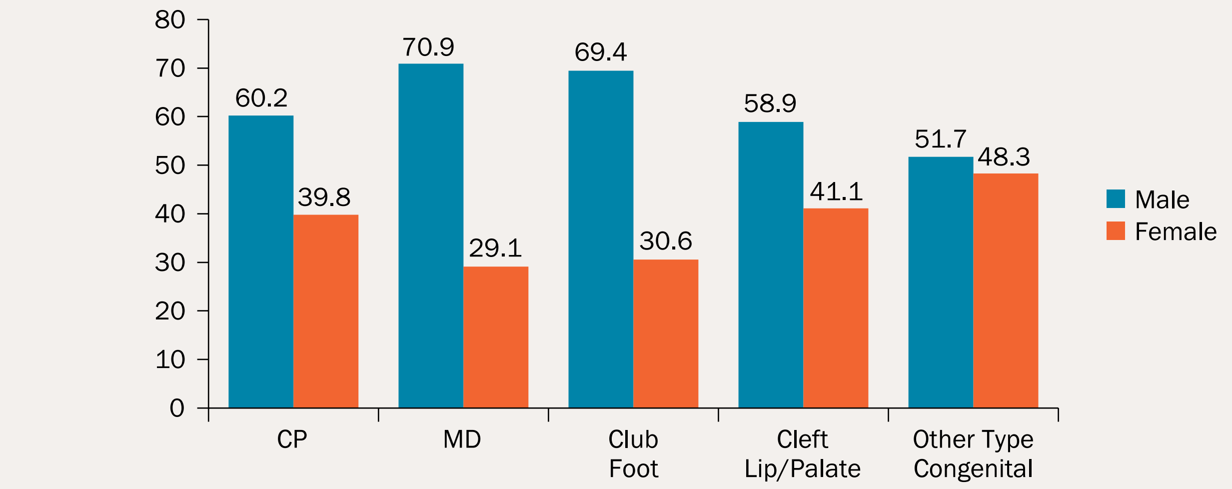
[12] Note as mentioned above, these are according to strict project criteria and causing significant loss of functioning. These numbers do not include children with health conditions causing mild/moderate impairment to physical functioning or other health conditions affecting children.

**Figure 11: Physical Impairments – Prevalent Health Conditions by Gender (% Cohort)**



## Parental Perception and Clinical Diagnosis

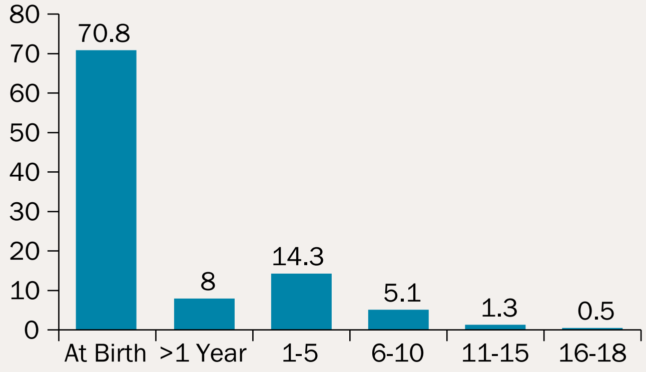
74.0% of children with clinically diagnosed significant physical impairments screened positive for disability as per the Washington Group questions (see page 14 for definition). Table 14 describes the core domain limitation responses. The majority of children with significant physical impairments were immobile (31.73%), unable to communicate (28.73%) and unable to self-care (33.04%) as a consequence of their impairments, highlighting the urgent need for greater rehabilitative support.

Caregivers responded that 70.8% of children with significant physical impairments were born with their impairments (Figure 12). Less than 7% of caregivers reported onset beyond 5 years of age. 6% (n=87) reported a significant disease during the mother's pregnancy. Table 15 (page 38) describes the clinically diagnosed health conditions of the children whose mothers had experienced disease during pregnancy and whose onset was reported to be under the age of 3.

**Table 14: Physical Impairment – Reported Degree of Difficulty Using WG Criteria**

| **Physical Impairments – Washington Group Questions Core domain limitations (% children with physical impairments)** | | | | |
|---|---|---|---|---|
| **Core Domains** | **No Difficulty** | **At least some difficulty** | **At least a lot of difficulty** | **Unable to do it at all** |
| Vision | 92.9 | 2.5 | 1.9 | 2.8 |
| Hearing | 85.6 | 4.7 | 3.9 | 5.9 |
| Mobility | 29.6 | 15.4 | 23.3 | 31.7 |
| Communication | 50.9 | 8.1 | 12.3 | 28.7 |
| Self Care | 43.0 | 10.9 | 13.0 | 33.0 |

**Figure 12: Physical Impairment – Reported Age of Onset (% Cohort)**



### Table 15: Physical Impairment – Significant Disease and Onset

| Physical Impairments – Significant Disease and Onset | | | |
|---|---|---|---|
| | **At birth (%)** | **0-3 years (%)** | **Total (%)** |
| Cleft Lip/Palate | 6.8 | 7.7 | 6.9 |
| Club Foot | 10.8 | 7.7 | 10.3 |
| Congenital Deformity | 4.1 | 0.0 | 3.4 |
| Genetic Disease | 4.1 | 0.0 | 3.4 |
| Hydrocephalus | 0.0 | 7.7 | 1.1 |
| Cerebral Palsy | 74.3 | 76.9 | 74.7 |
| **Total (%)** | **100 (n=74)** | **100 (n=13)** | **100 (n=87)** |

### Table 16: Physical Impairment – Apparent Cause

| Physical Impairments – Apparent Cause | | | | | |
|---|---|---|---|---|---|
| | **Unknown (%)** | **Trauma (%)** | **Illness (%)** | **Delayed Crying (%)** | **Total** |
| Cerebral Palsy | 6.5 | 1.9 | 27.5 | 64.1 | 100 (953) |
| Club Foot | 22.2 | 0.7 | 18.1 | 59.0 | 100 (144) |
| Other Type Congenital | 19.5 | 9.3 | 26.3 | 44.9 | 100 (118) |
| Muscular Dystrophy | 25.5 | 2.7 | 29.1 | 42.7 | 100 (110) |
| Cleft Lip/Palate | 29.0 | 1.9 | 26.2 | 43.0 | 100 (117) |
| Genetic | 29.4 | 0.0 | 23.5 | 47.1 | 100 (85) |
| Trauma/Burn | 11.3 | 71.7 | 30.2 | 39.6 | 100 (53) |
| Hydrocephalus | 20.5 | 2.6 | 38.5 | 38.5 | 100 (39) |
| Polio | 7.1 | 3.6 | 46.4 | 42.9 | 100 (28) |
| Spina Bifida | 21.4 | 7.1 | 14.3 | 57.1 | 100 (14) |
| Amputee | 16.7 | 33.3 | 8.3 | 41.7 | 100 (12) |
| Spinal Cord Injury | 10.0 | 0.0 | 20.0 | 70.0 | 100 (10) |
| Rickets | 10.0 | 0.0 | 40.0 | 50.0 | 100 (10) |
| Others | 14.1 | 11.1 | 38.0 | 36.8 | 100 (234) |
| **Total** | **13.2** | **5.4** | **27.8** | **53.5** | **100** |

For the majority of health conditions causing significant physical impairment, parents reported a delay in crying as the apparent cause. A delay in crying (often related to pre-natal defects or birth trauma) is often perceived as an attributor to disability [40] – even reported here in 42.9% of polio and 39.6% of trauma/burn cases.

6% (n=99) of respondents stated that the parents or relatives of the child had the same problem in terms of physical functioning, suggesting possible hereditary links. 8% (n=130) of caregivers reported parental cosanguinuity of the child. Cerebral Palsy accounted for the vast majority of reported cases of parental cosanguinouity and parents or caregivers experiencing the same problem amongst parents of children with significant physical impairments (Figures 13 and 14).

**Figure 13: Physical Impairment – Parental Cosanguineouity (% of Cosanguineous Cases)**

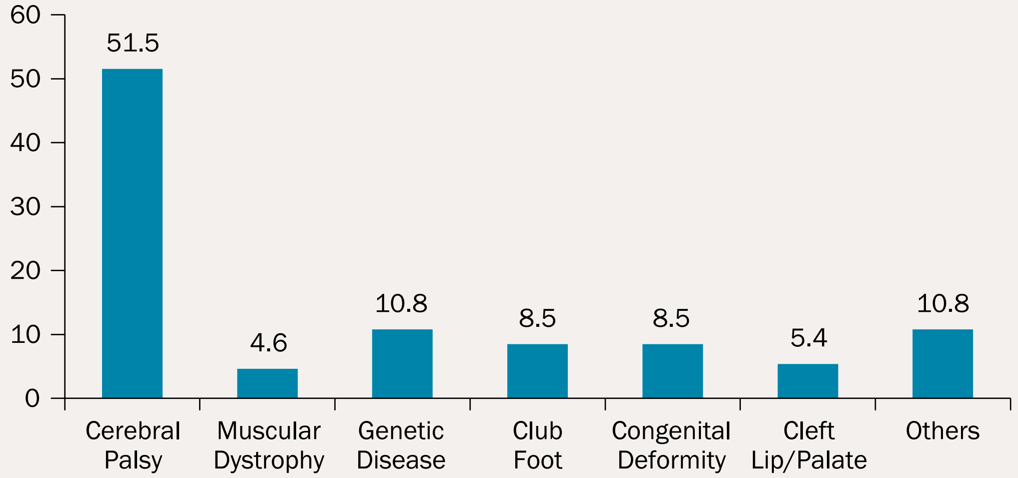
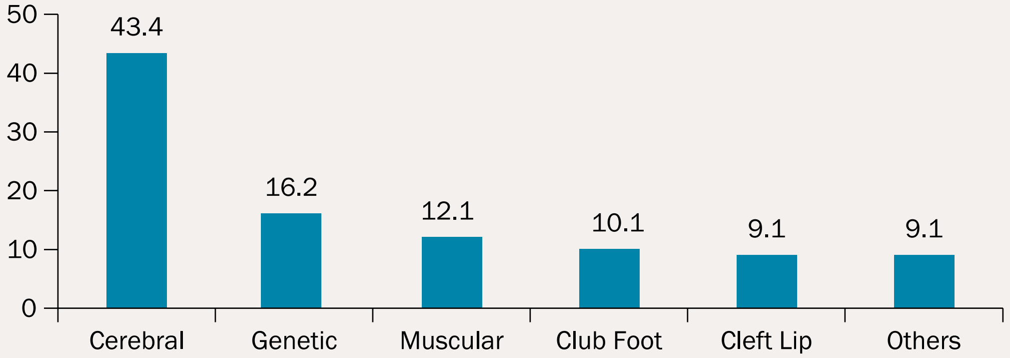


**Figure 14: Physical Impairment – Parents/Caregivers Same Problem (% of Those With Same Problem)**



## Education

Figure 15 shows the educational status of school-aged children (over the age of 5) with significant physical impairments in the cohort. 61.3% of school age children were not in any type of education, and amongst those who were, 24.1% aged 11 or above remained in primary school or Madrassas, implying that they were not able to progress to secondary school grades alongside their peers. Only four children from the physical impairment cohort attended a special school, one of whom was also attending mainstream school.

**Figure 15: Physical Impairment – Educational Status (% of Age Group)**

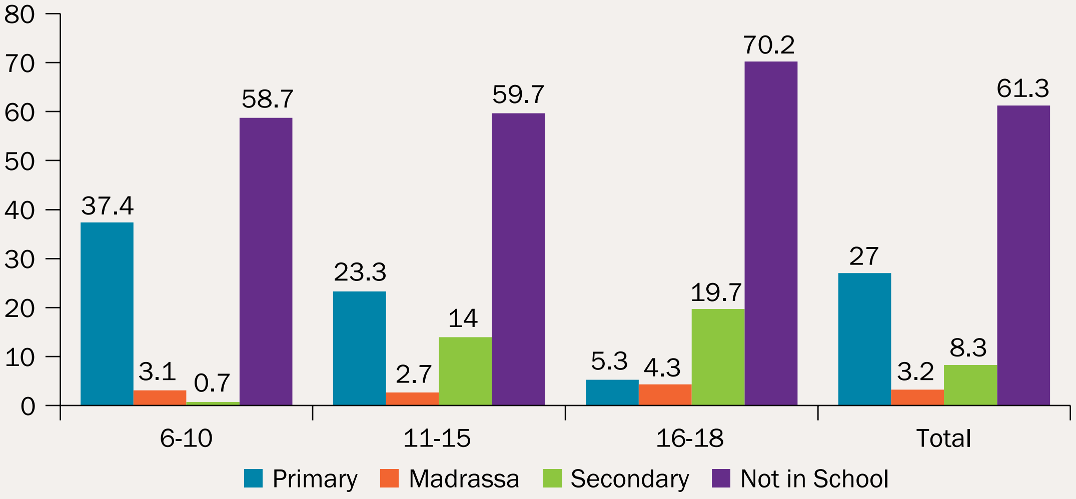
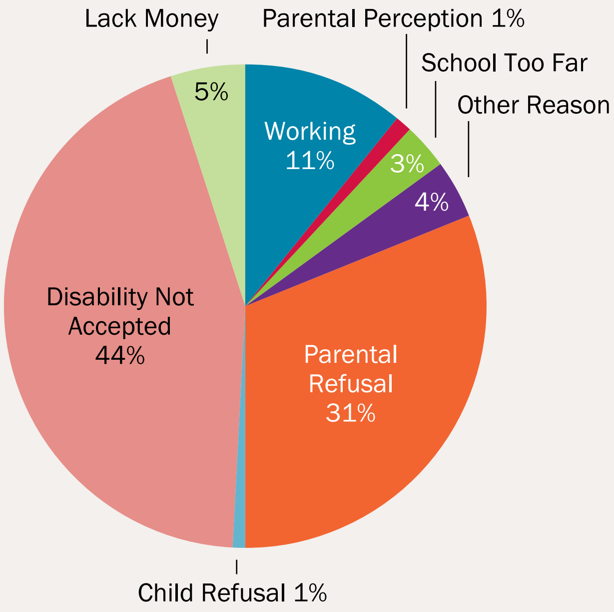


Figure 16 gives the reasons provided by respondents for school-aged children with significant physical impairments (n=644) not attending school (non mutually-exclusive reasons). The child's disability (44%) and parental refusal (31%) were the two most frequent reasons cited, as with all other impairment types and health conditions targeted in the study. More information on this can be found in the summary qualitative reports later in this report (page 85).

**Figure 16: Physical Impairment – Reasons not in School**



## Previous Rehab Support

47.3% of the physically impaired children in the study had previously received rehabilitative services or related support. Of these, approximately half (20.4% of all children with physical impairments) had received advice only. Very few children had accessed Assistive Devices, Surgeries, Therapeutic Exercises or Other related services.

**Table 17: Physical Impairment – Previous Rehabilitative Support/Services Received**

| Physical Impairment – Previous Rehabilitative Support/Services Received (% Group) [13] | | | | | | |
|---|---|---|---|---|---|---|
| **No Service Received** | **Advice Only** | **Advice** | **Assistive Device** | **Surgery** | **Therapy Exercises** | **Total (n)** |
| 53.3% | 20.4% | 33.0% | 2.7% | 4.6% | 17.0% | 100 (1,601) |

The most frequent reason for never having previously sought rehabilitation for the child was a lack of money to use the facility, followed by lack of awareness, implying that despite the existence of services, they were not accessible or known to a large proportion of the cohort. See the Barriers to Access summary report on page 79 for further information about this.

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[13] Type of service previously received may be greater than one.

# Blindness and Visual Impairment

Severe bilateral visual impairment or blindness (presenting visual acuity of less than 6/60 in the better eye) accounted for 184 children among those examined (a prevalence of 0.7/1,000 children or 295 children per million population).

As with other types of impairments targeted in the study, there were a higher proportion of male children than female children identified with severe visual impairment (59.8% versus 40.2%) in the cohort (Table 18).

**Table 18: Visual Impairment – Cohort Descriptives**

| Visual Impairment Cohort Descriptives | | | | | |
|---|---|---|---|---|---|
| | **<=5** | **6-10** | **11-15** | **16-18** | **Total** |
| Male | 33 | 40 | 18 | 19 | 110 (59.8%) |
| Female | 16 | 26 | 18 | 14 | 74 (40.2%) |
| **Total** | **49 (26.6%)** | **66 (35.9%)** | **36 (19.6%)** | **33 (17.9%)** | **184** |

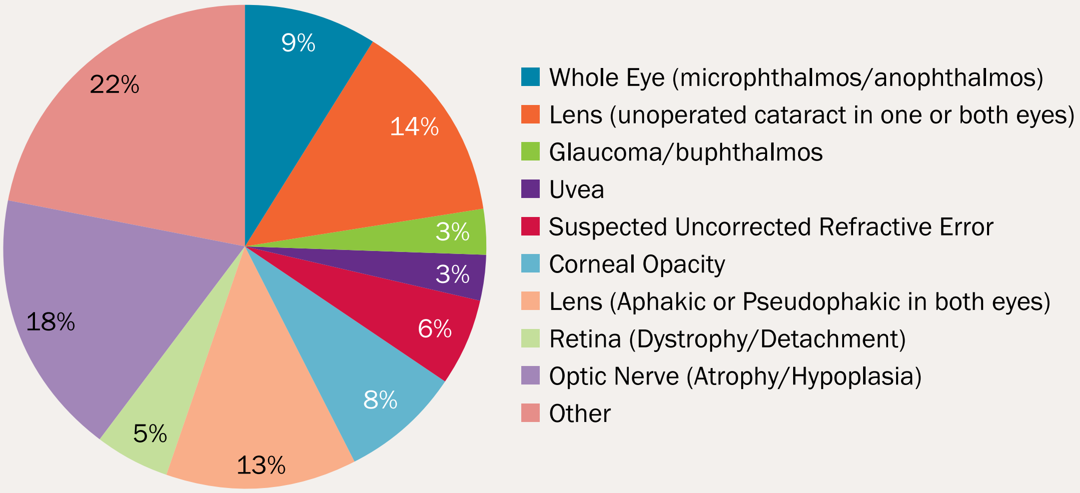
**Table 19: Visual Impairment – Cohort**

| Visual Impairment – Cohort | | |
|---|---|---|
| | **n** | **% Cohort** |
| VI only | 121 | 65.76 |
| VI & Epilepsy | 2 | 1.09 |
| VI & Epilepsy & PI | 10 | 5.43 |
| VI & Epilepsy & PI & HI | 3 | 1.63 |
| VI & PI | 37 | 20.11 |
| VI & PI & HI | 7 | 3.8 |
| VI & HI | 4 | 2.17 |
| **Total** | **184** | **100** |

34% of visually impaired children in the cohort presented with multiple impairments; 23% visually impaired as a component of Cerebral Palsy pathology (Table 19).

Corneal opacity accounted for 22% of severe visual impairment diagnosed in the study, whilst optic nerve conditions and un-operated cataracts accounted for the second and third most prevalent underlying causes of severe bilateral visual impairment (18% and 14% of cases respectively) – see Figure 17.

**Figure 17: Cause of Blindness/Severe VI**



## Parental Perception and Clinical Diagnosis Amongst Visually Impaired Children

77.2% of children with clinically diagnosed bilateral visual impairments in the study screened positive for disability as per the Washington Group Questions, meaning that 22.8% screened negative according to parent-reported disability. Table 20 shows the degree of difficulty in exercising individual core domains reported. 71.7% of respondents responded that the child had some difficulty, alot of difficulty or an inability in seeing, whilst 28.3% of respondents for children with bilateral visual impairments stated no problem in vision at all. This suggests a lack of awareness of caregivers regarding the child's impairment, despite a clinically diagnosed bilateral visual impairment.

**Table 20: Visual Impairment – Reported Degree of Difficulty Using WG Criteria**

| Visual Impairment – Washington Group Question Core Domain Limitations (% Children with SVI/Blindness) | | | | |
|---|---|---|---|---|
| **Core Domains** | **No difficulty** | **At least some difficulty** | **At least a lot of difficulty** | **Unable to do it at all** |
| Vision | 28.3 | 13.6 | 31.5 | 26.6 |
| Hearing | 87.5 | 2.7 | 3.8 | 6.0 |
| Mobility | 69 | 6.0 | 8.2 | 16.8 |
| Communication | 73.4 | 4.9 | 5.4 | 16.3 |
| Self Care | 56.5 | 9.2 | 12.0 | 22.3 |

51% of children were blind/SVI at birth (Figure 18). Only one caregiver reported the mother contracting a serious disease during pregnancy, whilst 7.6% (n=14) reported similar problems amongst other family members and 13% (n=24) reported parental consanguinity.

Respondents attributed delayed crying in 45.1% of cases as the apparent cause of severe visual impairment, followed by illness (39.1%) and trauma (1.1%). 14.7% of respondents could not attribute a cause for the impairment (Table 21).

**Figure 18: Visual Impairment – Reported Age of Onset (% Cohort)**

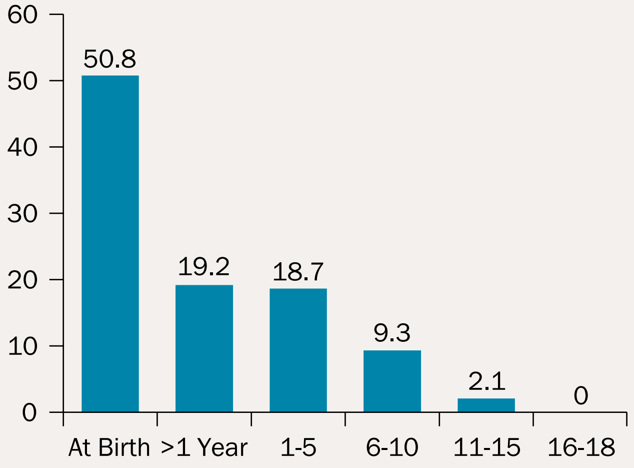


**Table 21: Visual Impairment – Apparent Cause**

| Visual Impairment – Apparent Cause | | | | | |
|---|---|---|---|---|---|
| | **Trauma** | **Illness** | **Delayed Crying** | **Unknown** | **Total % (n)** |
| Visual Impairment only | 1.7 | 37.2 | 45.5 | 15.7 | 100 (121) |
| Visual Impairment plus other impairments | 0.0 | 42.9 | 44.4 | 12.7 | 100 (63) |
| **Total % (n)** | **1.1 (2)** | **39.1 (72)** | **45.1 (83)** | **14.7 (27)** | **100 (184)** |

## Education

39% of school-aged children with severe visual impairments in the cohort attended school, although this decreased with age. (Figure 19). Two additional children attended a special school for the blind but did not attend mainstream education.

**Figure 19: Visual Impairment – Eductional Status (% Cohort)**

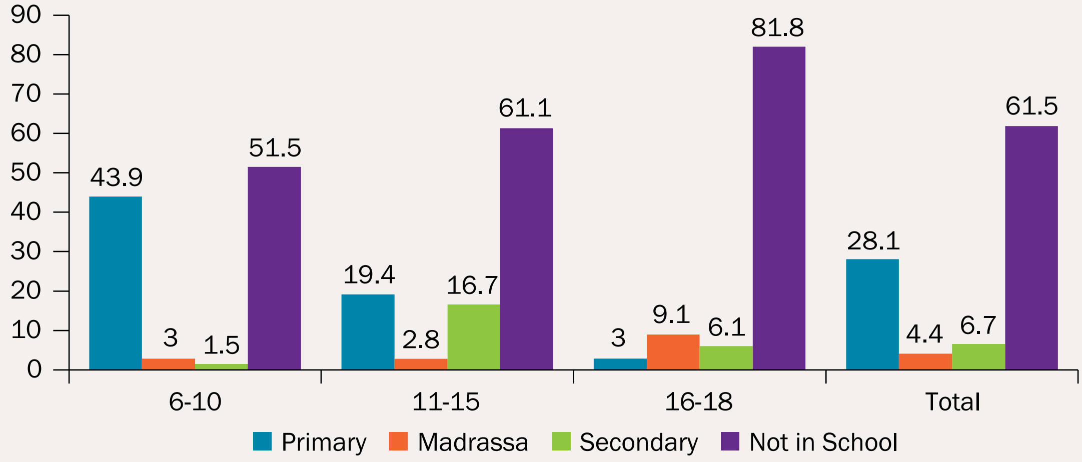
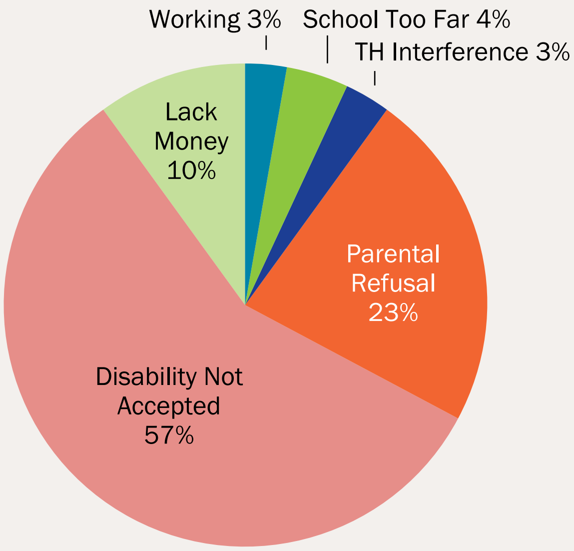


Figure 20 lists the reasons that 61% of school-aged children with visual impairments were not in school. Lack of acceptance by the school (57%) and parental refusal (23%) were again the most cited reasons, implying a need for further examination of the inclusivity of the Bangladeshi education system and the capacity of school teachers to include children with alternative learning needs in the classroom.

**Figure 20: Visual Impairment – Reasons not in School**



## Previous Rehab Support

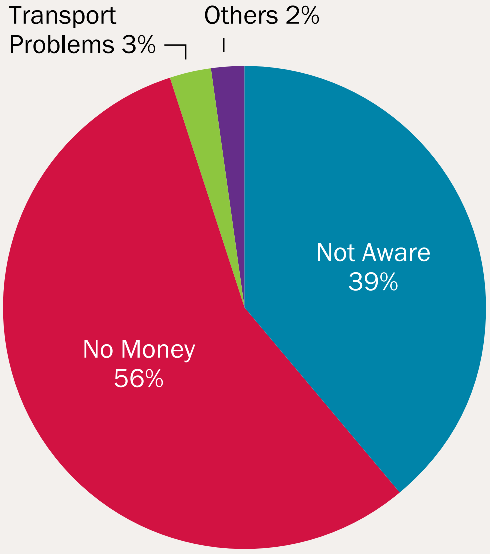
46.7% of children with severe visual impairments in the study had previously received rehabilitative services or related support. 22.3% of these however had received advice only (Table 22), again implying that the presence of appropriate services is not sufficient in ensuring access and use.

The most common reasons given for not having previously received rehabilitative services included lack of money (56%) and awareness (39%) – Figure 21.

**Table 22: Visual Impairment – Previous Rehab Received**

| Visual Impairment – Previous Rehabilitative Support/Services Received (% Group) [14] | | | | | | |
|---|---|---|---|---|---|---|
| **No Service Received** | **Advice Only** | **Advice** | **Assistive Device** | **Surgery** | **Therapy Exercises** | **Total (n)** |
| 53.3 | 22.3 | 33.2 | 3.8 | 9.2 | 5.4 | 100 (184) |

**Figure 21: Visual Impairment – Reasons no Rehab Received**



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[14] Type of service previously received may be greater than one.

## Deafness and Hearing Impairment

Moderate or bilateral hearing impairment was diagnosed in 12.5% of the KI Listed children examined (n=513), leading to an estimate of 2.0 per 1,000 children in Bangladesh. However, due to a large proportion of children suffering from discharging ears, or as a consequence of communication difficulties, this could only be confirmed via OAE (failure in both ears) or audiometry (>30 dBHL in both ears) in 16.7% of cases (a confirmed prevalence of 0.3/1,000). Based on preliminary diagnoses by a trained ENT specialist, the figures reported here are based on all cases of moderate or severe bilateral HI, whether or not confirmed via OAE or audiometry.

22.6% of children in the HI cohort had multiple impairments or health conditions targeted by the study (Table 24), of which 15.4% were part of the child's CP pathology.

## Parental Perception and Clinical Diagnosis Amongst Hearing Impaired Children

84.4% of children with moderate or severe bilateral hearing impairments screened positive for disability using the parent-report Washington Group Questions. Table 25 denotes activity limitations reported for children with moderate or severe hearing impairment in the study. 18.1% of respondents reported no problem in hearing amongst children diagnosed with moderate or severe hearing impairments, implying that almost one fifth of respondents did not perceive the child's hearing impairment. Moreover, 55% of the hearing cohort was reported to be unable to communicate at all, highlighting the need for early intervention programs. Studies have shown that a failure to detect and manage congenital hearing impairment or hearing impairment developed within the first year of the child's life can have irreversible impact on speech and development [41].

### Table 23: Hearing Impairment – Cohort Descriptives

**Hearing Impairment Cohort Descriptives**

| | <=5 | 6-10 | 11-15 | 16-18 | Total |
|---|---|---|---|---|---|
| Male | 73 | 90 | 58 | 51 | 272 |
| Female | 50 | 76 | 75 | 40 | 241 |
| **Total** | **123** | **166** | **133** | **91** | **513** |

### Table 24: Hearing Impairment – Cohort

**Hearing Impairment – Cohort**

| | n | % Cohort |
|---|---|---|
| HI only | 397 | 77.39 |
| HI & Epilepsy | 7 | 1.36 |
| HI & PI & Epilepsy | 19 | 3.7 |
| HI & VI & PI & Epilepsy | 3 | 0.58 |
| HI & PI | 76 | 14.81 |
| HI & PI & VI | 7 | 1.36 |
| HI & VI | 4 | 0.78 |
| **Total** | **513** | **100** |

### Table 25: Hearing Impairment – Reported Degree of Difficulty Using WG Criteria

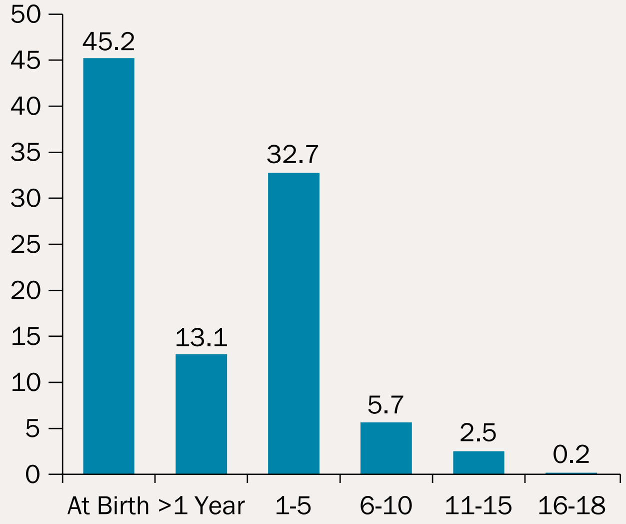
**Hearing Impairment – Washington Group Questions Core Domain Limitations (% Hearing Impaired)**

| Core Domains | No Difficulty | At least some difficulty | At least a lot of difficulty | Unable to do it at all |
|---|---|---|---|---|
| Vision | 94.3 | 1.8 | 1.2 | 2.7 |
| Hearing | 18.1 | 10.5 | 20.9 | 50.5 |
| Mobility | 82.3 | 3.7 | 3.3 | 10.7 |
| Communication | 26.6 | 5.3 | 12.9 | 55.2 |
| Self Care | 76.4 | 7.4 | 3.5 | 12.7 |

Parents reported that 45.2% of children with bilateral hearing impairments had been born with the condition, whilst 13.1% reported the problem occurring within the first year of the child's life and a further 32.7% before the child's six birthday, providing further weight to the argued importance of early identification and management programs (Figure 22).

Tables 26 and 27 document the clinical history of children with moderate or severe bilateral impairments diagnosed in the study. 8.0% of parents of children in this cohort were consanguineous and 9.2% of parents or caregivers were reported to have the same problem as the child. 2.2% of respondents stated that caregivers were both consanguineous and had the same problem as the child, suggesting a possible hereditary link. Hereditary hearing impairment is much higher in developing countries than in developed countries, with the impact of consanguinity on inherited deafness much studied [42]. As with other impairment types, delayed crying was cited as the apparent cause of impairment by 50.1% of respondents.

### Figure 22: Hearing Impairment – Reported Age of Onset (% Cohort)



### Table 26: Hearing Impairment – Clinical History (% Cohort)

| Hearing Impairment – Clinical History (% Cohort) | | | | |
|---|---|---|---|---|
| | | **Parents/Caregivers Same Problem** | | |
| | | **Yes** | **No** | **Total % (n)** |
| Parents Consanguineous | Yes | 2.15 | 5.87 | 8.02 |
| | No | 7.05 | 84.93 | 91.98 |
| | **Total** | **9.20** | **90.80** | **100 (513)** |

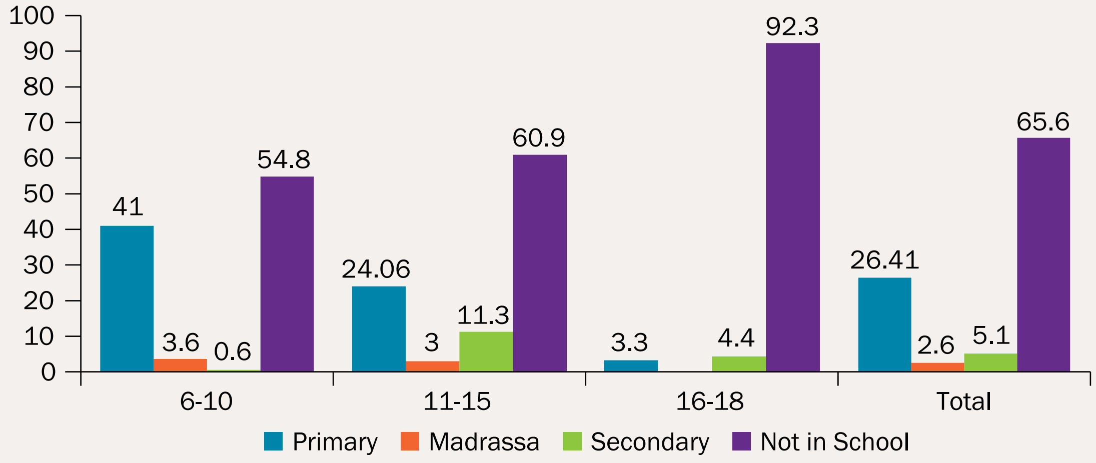
### Table 27: Hearing Impairment – Apparent Cause

| Hearing Impairment – Apparent Cause (% Cohort) | | | | | |
|---|---|---|---|---|---|
| | **Trauma** | **Illness** | **Delayed Crying** | **Unknown** | **Total %** |
| Hearing Impairment only | 1.3 | 28.0 | 48.9 | 21.9 | 100 |
| Hearing Impairment plus other impairments | 1.7 | 35.3 | 54.3 | 8.6 | 100 |
| **Total %** | **1.4** | **29.6** | **50.1** | **18.9** | **100** |

## Education

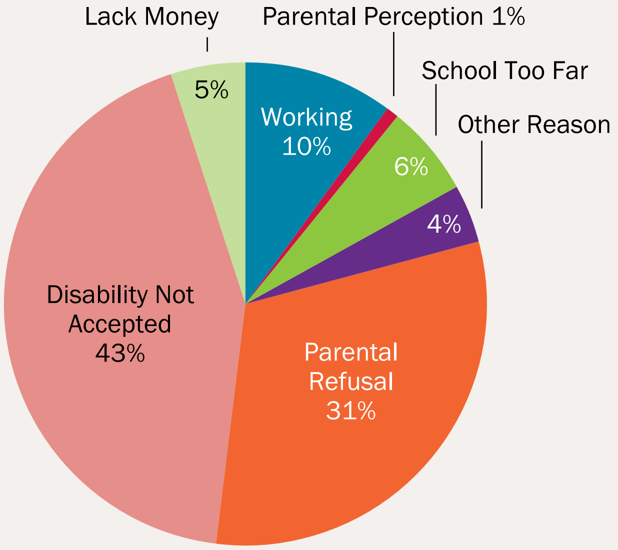
34.1% of school aged children with hearing impairments were currently attending mainstream school, although this included only 7.7% of children over the age of 15, with 92.3% of children aged 16 or older in the cohort out of school (Figure 23). A small minority (9.1%) of children with hearing impairments in the study attended Madrassa education. Two children from amongst the cohort with bilateral hearing impairments attended special school.

**Figure 23: Hearing Impairment – Educational Status (% Age Group)**



The low numbers of children attending school from amongst this cohort perhaps reflect parental report of limited communication amongst children with moderate or severe bilateral hearing impairment in the study and of lack of acceptance by schools of the child's disability (Figure 24). 31% of respondents stated that the parents of the child refused to send the child to school, although the reasons for this as discussed in the Qualitative Report (page 85) are multiple and include parental fear that the child will be bullied or excluded.

**Figure 24: Hearing Impairment – Reasons not in School**



## Previous Rehab Support

70.2% of children with bilateral hearing impairments in the study had never previously received rehabilitation services or support (Table 28), with 3% receiving Assistive Devices (eg. hearing aid) or surgery. As in other groups in the study, a lack of money (61%) and awareness of service availability (38%) were the biggest barriers for caregivers (Figure 25).

**Figure 25: Hearing Impairment – Reasons no Rehab Received**

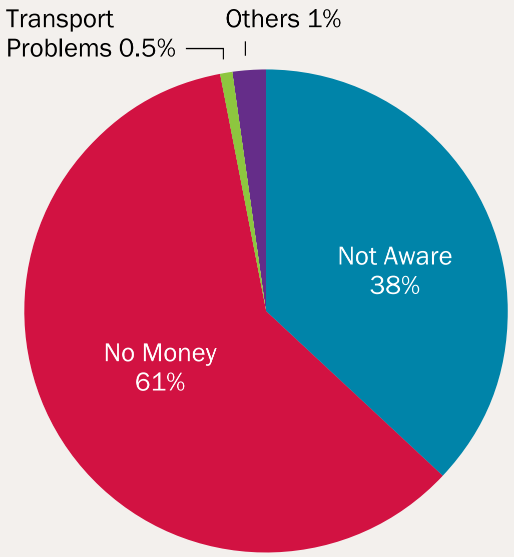


**Table 28: Hearing Impairment – Previous Rehab Received**

| Hearing Impairment – Previous Rehabilitative Support/Services Received (% Group)[15] | | | | | | |
|---|---|---|---|---|---|---|
| **No Service Received** | **Advice Only** | **Advice** | **Assistive Device** | **Surgery** | **Therapy Exercises** | **Total (n)** |
| 70.2 | 20.1 | 23.2 | 1.6 | 1.4 | 3.3 | 100 (513) |

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[15] Type of service previously received may be greater than one.

## Generalised Tonic-Clonic Seizures (Epilepsy)

The KIs identified 390 children with epilepsy (generalised tonic-clonic seizures) in the study, amounting to a prevalence of 1.5 per 1,000 children in Bangladesh. Table 29 describes the gender and age characteristics of this group.

**Table 29: Epilepsy – Cohort Descriptives**

| Epilepsy – Cohort Descriptives | | | | | |
|---|---|---|---|---|---|
| | **<=5** | **6-10** | **11-15** | **16-18** | **Total** |
| Male | 55 | 71 | 65 | 49 | 240 (61.5%) |
| Female | 31 | 47 | 39 | 33 | 150 (38.5%) |
| **Total** | **86 (22.0%)** | **118 (30.2%)** | **104 (26.7%)** | **82 (21.0%)** | **390 (100%)** |

A large proportion of children with epilepsy in the study had additional impairments meeting the study criteria (Table 30).

37.7% of children with epilepsy in the examined children had physical impairments, with 33% of the epilepsy subjects additionally being diagnosed with Cerebral Palsy. This finding is in common with another study of child epilepsy in Bangladesh that found co-morbidities between epilepsy and major motor impairments in 41.1% of the cohort [43].

**Table 30: Epilepsy – Cohort**

| Epilepsy – Cohort | | |
|---|---|---|
| | **n** | **% Cohort** |
| Epilepsy Only | 202 | 51.79 |
| Epilepsy & PI | 147 | 37.69 |
| Epilepsy & HI | 7 | 1.79 |
| Epilepsy & VI | 2 | 0.51 |
| Epilepsy & HI & PI | 19 | 4.87 |
| Epilepsy & VI & PI | 10 | 2.56 |
| Epilepsy & VI & HI & PI | 3 | 0.77 |

## Parental Perception and Clinical Diagnosis Amongst Children Diagnosed with Epilepsy

56.2% (n=219) of children diagnosed with epilepsy in the study screened positive for disability using the Washington Group parent report questions. Of these, 22% (n=49) had epilepsy only, whilst the rest had additional targeted study impairments. 11.8% and 20.2% of respondents for this cohort reported some level of difficulty in the child's ability to see or hear respectively, whilst mobility, communication and self care difficulties were reported amongst 44.1%, 52.8% and 49.7% of the cohort respectively (Table 31).

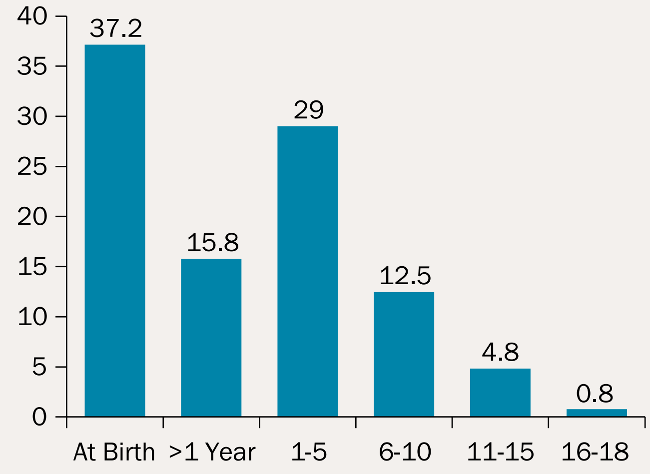
### Table 31: Epilepsy – Reported Degree of Difficulty Using WG Criteria

**Epilepsy – Washington Group Questions Core Domain Limitations**

| Core Domains | No Difficulty | At least some difficulty | At least a lot of difficulty | Unable to do it at all |
|---|---|---|---|---|
| Vision | 88.2 | 3.6 | 3.3 | 4.9 |
| Hearing | 79.8 | 7.2 | 5.1 | 7.9 |
| Mobility | 55.9 | 10.0 | 9.0 | 25.1 |
| Communication | 47.2 | 12.3 | 11.3 | 29.2 |
| Self Care | 50.3 | 8.7 | 7.7 | 33.3 |

52.9% of respondents reported the presence of epilepsy in the child either from birth or within the first year of life (Figure 26).

### Figure 26: Epilepsy – Reported Age of Onset (% Cohort)



3 respondents stated that the child's mother had taken strong medicines or drugs during her pregnancy, and Table 32 shows the presence of consanguinity or family history of epilepsy amongst the examined children, which was lower than amongst other groups in the cohort. 60.3% of respondents reported delayed crying as the apparent cause of the child's condition, whilst 27.4% reported illnesses (Table 33). Viral infections (such as aseptic meningitis amd encephalitis), parasitic diseases (such as malaria) and poor peri-natal care are often attributed to the increased prevalence of epilepsy in developing or tropical countries in comparison to developed or non-tropical countries [44].

### Table 32: Epilepsy – Clinical History

**Epilepsy – Clinical History (% Cohort)**

| | | **Parents/Caregivers Same Problem** | | |
|---|---|---|---|---|
| | | **Yes** | **No** | **Total % (n)** |
| Parents Consanguineous | Yes | 0.8 | 5.6 | 6.4 |
| | No | 5.1 | 88.5 | 93.6 |
| | **Total** | **5.9** | **94.1** | **100 (390)** |

### Table 33: Epilepsy – Apparent Cause

**Epilepsy – Apparent Cause (% Cohort)**

| | Trauma | Illness | Delayed Crying | Unknown | Total % (n) |
|---|---|---|---|---|---|
| Epilepsy only | 1.5 | 23.3 | 59.9 | 15.3 | 100 |
| Epilepsy plus other impairments | 1.6 | 31.9 | 60.6 | 5.9 | 100 |
| **Total % (n)** | **1.5** | **27.4** | **60.3** | **10.8** | **100 (390)** |

## Education

Figure 27 shows the percentage of school-aged children identified with epilepsy in the study in education. 28.4% of children with epilepsy attended school (significantly less than the average across all disability types of 38.9%). As with other cohorts in the study, non-acceptance of disability by the school and parental refusal to send the child to school (41% and 38% of reasons cited respectively) were the most frequently reported barriers to education (Figure 28). Please refer to the Bangladesh Qualitative Report Summary (page 85) for further discussion of stigmatisation of children with epilepsy and fear of seizure onset are amongst peers.

**Figure 27: Epilepsy – Educational Status (% Age Group)**

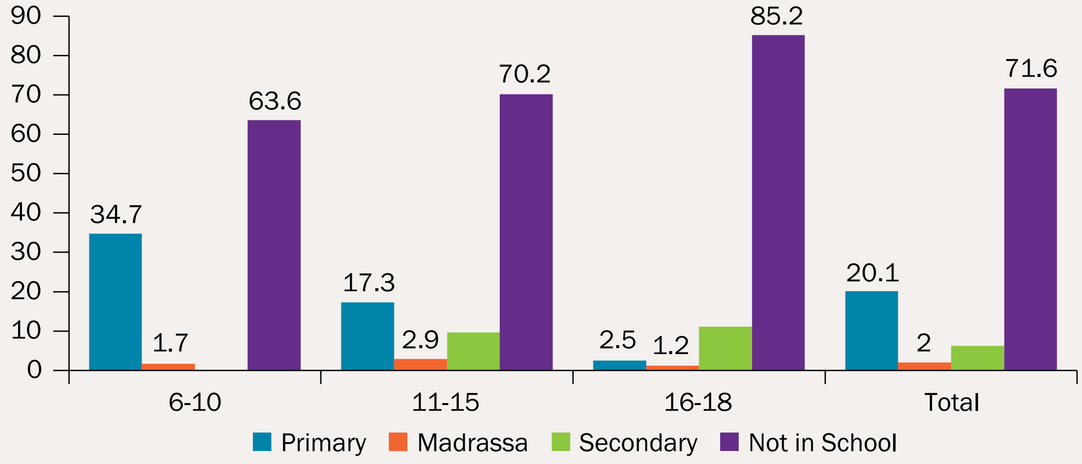
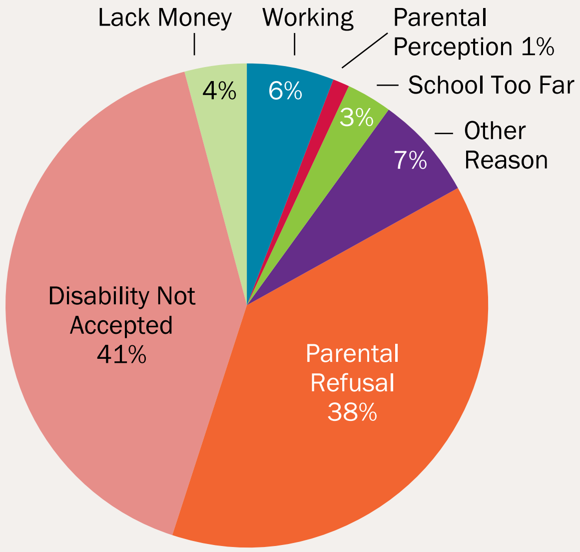


**Figure 28: Epilepsy – Reasons not in School**



## Previous Rehabilitation Support

When asked whether they had previously sought rehabilitation support or services, 52.1% of caregivers of children with epilepsy responded that they had, with half of these (25.9% of the entire epilepsy cohort) stating that they had received advice only (Table 34). However, caregivers of children who were diagnosed with epilepsy were asked two additional questions on whether they had previously sought medical advice on the child's seizures and whether or not the child had ever received Anti-Epileptic drugs (AEDs). 55.6% of respondents to this question stated that they had seen a medical professional regarding the child's seizures previously, and of these, 91.4% (50.8% of the overall epilepsy cohort) had previously received medication for the child's condition (Table 35). The discrepancy in responses highlights understandings of "rehabilitation" in this context and the classification of AEDs and potentially epilepsy by caregivers as outside the remit of rehabilitation.

### Table 34: Epilepsy – Previous Rehab Received

**Epilepsy – Previous Rehabilitative Support/Services Received (% Cohort)** [16]

| No Service Received | Advice Only | Advice | Assistive Device | Surgery | Therapy Exercises | Total (n) |
|---|---|---|---|---|---|---|
| 47.9 | 25.9 | 41.8 | 1.3 | 0.5 | 12.8 | 100 (390) |

### Table 35: Previous AED Services Sought

**Epilepsy – Previous AED Services Sought (% Cohort)**

| | | Does the child have medication? | | |
|---|---|---|---|---|
| | | **Yes** | **No** | **Total % (n)** |
| Has child been seen by medical person for this problem? | Yes | 50.8 | 4.9 | 55.6 |
| | No | 1.3 | 43.1 | 44.4 |
| | **Total** | **52.1** | **47.9** | **100 (390)** |

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**16** Type of service previously received may be greater than one.

# Results: Bangladesh Follow Up

**The following data relates to information gathered from 267 children in Sirajganj and Natore one year post KIM Camp. All interventions referred to were offered, free of charge, through the KIM study (see page 21 – methodology). The data includes children from the pilot, and the sampling frame was based on a random selection of children referred for services from the initial KIM Camps, proportional by numbers referred with different impairments/health conditions.**

**The purpose was to establish the programmatic impact of the study – i.e. whether children had undertaken their recommended referral, and if so, what the impact of that intervention had been. Conversely, if they had not undertaken the recommended and directly funded intervention, what the reasons/barriers to this had been. This latter objective was also addressed in the Barriers to Uptake work undertaken by Robin Nesbitt and Dr. Juliet Bedford (see page 79 for a summary of this work).**

## Descriptives

Table 36 outlines the age, gender and impairment/health condition diagnosis of the follow up cohort, which was chosen proportionally to represent the quantity of children with each targeted impairment type or health condition identified in the study.

**Table 36: Follow Up Cohort Descriptives**

| Follow Up Cohort Descriptives | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | **Impairment/Health Condition** | | | | | | | |
| | | **Physical (not CP)** | **Visual** | **Hearing** | **Epilepsy** | **Other** | **CP** | **Multiple** | **Total n (%)** |
| Age | <=5 | 37 | 1 | 1 | 2 | 4 | 49 | 2 | 96 (36.0%) |
| | 6-11 | 24 | 1 | 3 | 9 | 3 | 39 | 0 | 79 (29.6%) |
| | 12-15 | 15 | 2 | 6 | 9 | 2 | 13 | 2 | 49 (17.2%) |
| | 16-18 | 11 | 0 | 2 | 14 | 1 | 14 | 1 | 43 (16.1%) |
| Gender | Male | 56 | 3 | 3 | 22 | 5 | 70 | 3 | 162 (60.7%) |
| | Female | 31 | 1 | 9 | 12 | 5 | 45 | 2 | 105 (39.3%) |
| **Total** | | **87 (32.6%)** | **4 (1.5%)** | **12 (4.5%)** | **34 (12.7%)** | **10 (3.8%)** | **115 (43.1%)** | **5 (1.9%)** | **267 (100%)** |

## Interventions Obtained Through KIM

**Table 37: Follow Up Cohort Descriptives**

| Follow Up Attributes and Interventions | | | | | | |
|---|---|---|---|---|---|---|
| | | **No. Interventions/Child** | | | | |
| | | **0** | **1** | **2** | **3** | **Total n (%)** |
| Impairment/ Health Condition | Physical (not CP) | 7 | 8 | 32 | 40 | 87 (32.6%) |
| | Visual | 2 | 0 | 0 | 2 | 4 (1.5%) |
| | Hearing | 2 | 2 | 8 | 0 | 12 (4.5%) |
| | Epilepsy | 0 | 1 | 30 | 3 | 34 (12.7%) |
| | Other | 1 | 1 | 6 | 2 | 10 (3.7%) |
| | CP | 1 | 8 | 69 | 37 | 115 (43.1%) |
| | Multiple | 0 | 2 | 2 | 1 | 5 (1.9%) |
| Gender | Male | 7 | 18 | 90 | 47 | 162 (60.7%) |
| | Female | 6 | 4 | 57 | 38 | 105 (39.3%) |
| Age Group | <=5 | 2 | 14 | 46 | 34 | 96 (36.0%) |
| | 6-10 | 3 | 5 | 46 | 25 | 79 (29.6%) |
| | 11-15 | 5 | 1 | 28 | 15 | 49 (18.4%) |
| | 16-18 | 3 | 2 | 27 | 11 | 43 (16.1%) |
| Income | <5k | 13 | 19 | 116 | 55 | 203 (76.0%) |
| | 5+k | | 4 | 32 | 30 | 66 (24.7%) |
| | **Total** | **13 (4.9%)** | **22 (8.2%)** | **147 (55.1%)** | **85 (31.8%)** | **267 (100%)** |

95.1% of children in the follow up had obtained a referral intervention through the KIM project, one year post screening, with an average of 2.1 referrals per child (Table 37). 4.9% (n=13) of children in the follow up sample had not undertaken their referral for a number of reasons as cited in Figure 29. Despite all interventions being funded by the study, several respondents (n=4) stated that they did not have enough money to attend the referrals. Please refer to the indepth Barriers and Predictors to Referral Uptake Summary (page 79) for further analysis of these barriers to uptake, including incremental (eg. transport/time away from other children under care) costs associated with referrals, and household heads disagreeing with the recommended intervention.

**Figure 29: Reasons for not Attending**

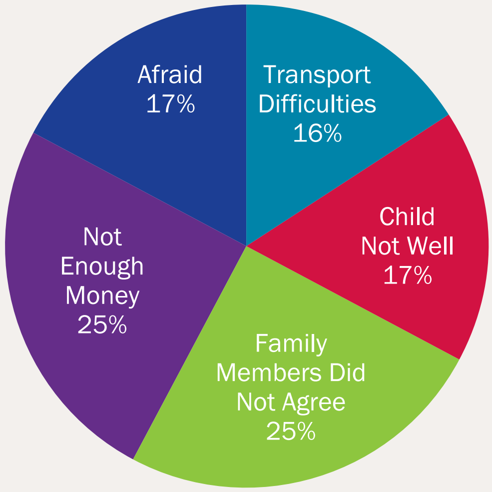
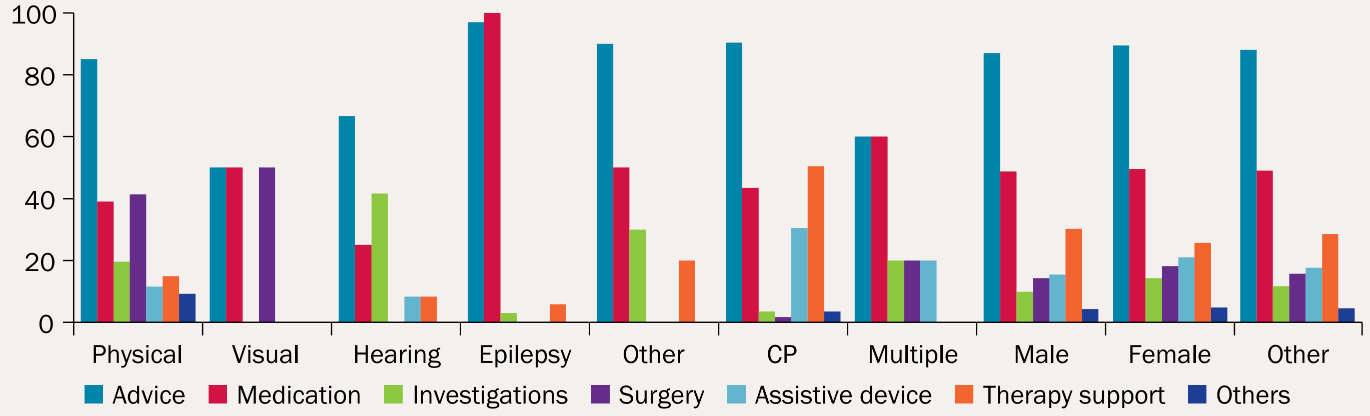


Table 38 and Figure 30 state the interventions that had been obtained by the cohort via the KIM project one year after the child attended the KIM medical screening camps. Of these, 49.1% of the cohort had received medication, 28.5% had received therapy support, 17.6% had received assistive devices, 15.7% had undergone surgery, 11.6% had been referred for further investigation and 4.5% had received miscellaneous interventions. 3.7% (n=10) had received advice only, with no further intervention taken to date.

### Table 38: Follow Up Referral Received

| Follow Up Referral Received (% Cohort) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **Advice** | **Medication** | **Investigations** | **Surgery** | **Assistive Device** | **Therapy Support** | **Others** | **Total % (n)** |
| Physical (not CP) | 85.1 | 39.1 | 19.5 | 41.4 | 11.5 | 14.9 | 9.2 | 100 (87) |
| Visual | 50.0 | 50.0 | 0.0 | 50.0 | 0.0 | 0.0 | 0.0 | 100 (4) |
| Hearing | 66.7 | 25.0 | 41.7 | 0.0 | 8.3 | 8.3 | 0.0 | 100 (12) |
| Epilepsy | 97.1 | 100 | 2.9 | 0.0 | 0.0 | 5.9 | 0.0 | 100 (34) |
| Other | 90.0 | 50.0 | 30.0 | 0.0 | 0.0 | 20.0 | 0.0 | 100 (10) |
| CP | 90.4 | 43.5 | 3.5 | 1.7 | 30.4 | 50.4 | 3.5 | 100 (115) |
| Multiple | 60.0 | 60.0 | 20.0 | 20.0 | 20.0 | 0.0 | 0.0 | 100 (5) |
| Male | 87.0 | 48.8 | 9.9 | 14.2 | 15.4 | 30.2 | 4.3 | 100 (162) |
| Female | 89.5 | 49.5 | 14.3 | 18.1 | 21.0 | 25.7 | 4.8 | 100 (105) |
| **Total** | **88.0** | **49.1** | **11.6** | **15.7** | **17.6** | **28.5** | **4.5** | **100 (267)** |

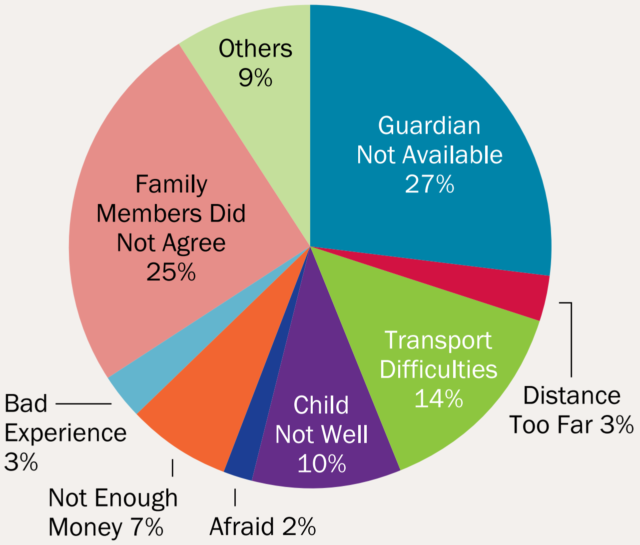
### Figure 30: Referral Received (% Cohort)



Amongst those in the sample who had attended their recommended referrals, 13% had only attended one session or treatment. 87% had returned for follow up treatment (s), although of these only 42.6% had returned for all follow up visits recommended in their referral.

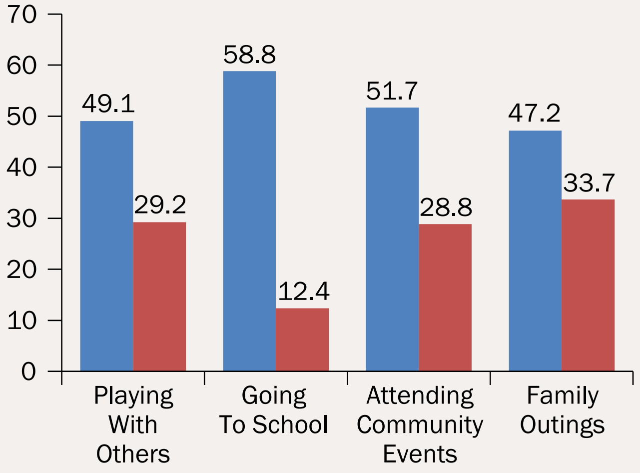
Those who had not completed their advised treatments (including follow up fittings for Assistive Devices (ADs), surgeries or renewed prescriptions) cited lack of guardian availability and lack of agreement from other family members as the major factors influencing their decision[17] (Figure 31). This data, alongside the Barriers to Uptake data, exemplify the multiple barriers often preventing caregivers of children with disabilities from obtaining appropriate services. These barriers frequently exist simultaneously, and differ substantially across individuals. Understanding and overcoming barriers to access of services is a key component in improving opportunities for children with physical impairments, sensory impairments or epilepsy as targeted in this study.

**Figure 31: Reason all Sessions not Attended**



## Impact of KIM on Children Identified with Targeted Impairments and Health Conditions in the Study

**Figure 32: Child Participation (% Cohort)**



All respondents in the follow up stated that attending the KIM screening camp had been beneficial to them/ their families. Up to a third of caregivers stated that the child's inclusion in playing with their peers and attending family and community events had improved as a consequence of the intervention (Figure 32) although for the majority of respondents, the child's participation level in terms of their peers, education, community events and family occasions had stayed the same as prior to the study.

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[17] For more on barriers referral take up, please refer to Barriers and Referrals to Service Uptake Summary on page 79.

# Bangladesh Medical Rehabilitation Costs

**The following results outline the cost of provision of referrals in the Bangladesh study, and how this information can be used to help plan appropriate services.**

**Table 39: Rehabilitation Costs**

| Impairment/Health Condition[18] | n (Study) | Prevalence/ Million General Population | Estimated National Magnitude | Average Cost per Child (£) | Cost/Mil Population (£) | 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 |
| **Total** | **2,334** | **3,736** | **579,112** | | **391,856** | **60,737,680** |

Table 39 outlines the unit costs of referral treatments and services for the targeted impairments covered in the study for which appropriate services were established, readily available and quantifiable. All medical referral costs amongst the cohort were met directly by the project's donors or provided free of cost by service providers. In instances where several referral options are possible (e.g. an assistive device or surgery), the figures account for the proportion of each referral type offered amongst the cohort. The table does not include cost estimates for non-treatable conditions, or conditions for which treatments were not readily available in the study districts (such as cosmetic surgeries for burn victims). It also does not include the hospital costs or the other expenses that parents may need to pay for to access treatment (food, transportation, loss of wage etc.). The referral service unit costs for which adequate information is known are multiplied by prevalence per thousand general population to estimate a cost per million, and national cost, of providing necessary referral services for the targeted childhood severe impairments.

The data is of great use to health-system planners, providing robust estimates on the country-specific scope and cost of appropriate referral systems. However, an important finding of the study was that the incidence of multiple impairments and of multiple appropriate referrals was significant across the cohort. This adds complexity to planning and costing appropriate, sustainable rehabilitative services, and further cost analysis into multiple impairments and referrals, as well as into the cost and prevalence of mild or moderate impairments is necessary to ensure maximum functionality of the methodology. Moreover, public healthcare sector in Bangladesh's limited ability to facilitate all necessary and appropriate rehabilitative care services independently, the role of Non Governmental Organisation (NGO)-managed services must also be established, and NGOs supported in their provision of rehabilitative services provided. Finally, given the extensive barriers to uptake elucidated in the study, mitigating obstacles and facilitating comprehensive follow up are important factors in planning rehabilitative services.

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[18] Please note that all are mutually exclusive, with multiple impairment costs highlighted.

# Bangladesh Household Survey

**The Bangladesh Household Survey was undertaken for comparison with the data collected via the Key Informant approach to identifying children with targeted sensory or physical impairments, or epilepsy in Bangladesh.**

## Descriptives

**Figure 33: Response Rate**

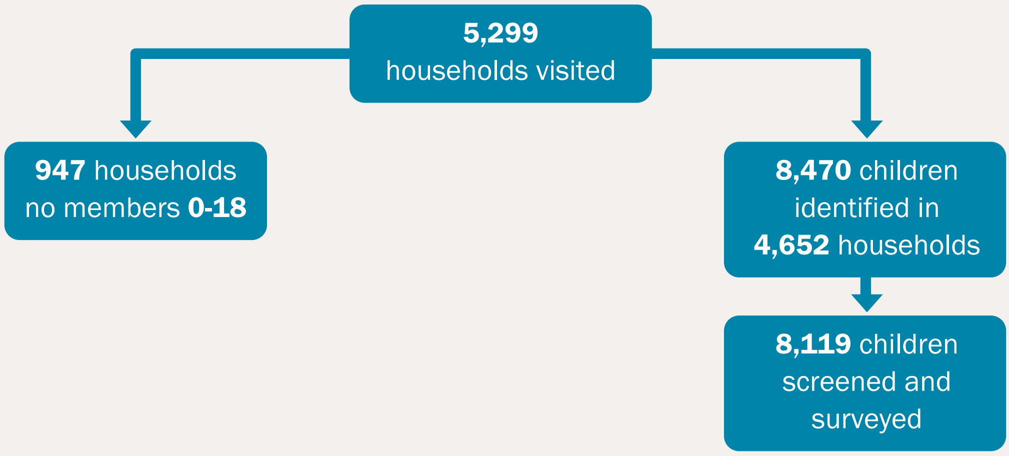

Table 40 outlines the age and gender of the 8,120 children screened and surveyed. As in the KIM, the gender ratio was almost equal (51% male and 49% female) and the majority of children screened were in the younger age brackets (69% under the age of 11).

Key Informants screened a population of 258,000 children for the targeted moderate or worse sensory or physical impairments, or epilepsy by spreading messages throughout their communities. The Household Survey screened 8,120 children in a systematic population-based survey for comparison, to ascertain whether the numbers identified by Key Informants would match those identified via a door-to-door survey or whether the KI Method did not identify all children matching the criteria.

**Table 40: Household Survey Cohort Descriptives**

| **Household Cohort Descriptives** | | | | | |
|---|---|---|---|---|---|
| | **Age (%)** | | | | |
| | **<=5** | **6-10** | **11-15** | **16-18** | **Total % (n)** |
| Male | 18% | 17% | 13% | 3% | 51% (4,120) |
| Female | 17% | 17% | 12% | 3% | 49% (4,000) |
| **Total** | **35% (2,860)** | **34% (2,783)** | **25% (2,036)** | **5% (441)** | **100% (8,120)** |

## Children Screening Positive for Targeted Impairments and Health Conditions

Table 41 outlines the numbers screened and matching the study criteria both using the Household Survey method and using the Key Informant method, and the respective prevalence figures established. In total, 119 children meeting the target criteria for moderate or worse sensory or physical impairments or epilepsy were diagnosed in the Household Survey, leading to a prevalence of 8.4 per 1,000 children with one or more of those conditions. 95% confidence intervals derived for both sets of figures (in brackets) show an overlap between the two methods in all categories except bilateral hearing impairments, the reasons for which are discussed in the Discussion section (page 88) [19]. This means that, with the exception of moderate or worse bilateral hearing impairment, KIs identified the same number of children as per the study criteria as were identified via a door to door Household Survey.

### Table 41: Bangladesh KIM vs. HH Survey

| **Bangladesh KIM vs. HH Survey Findings** | | | | |
|---|---|---|---|---|
| | **KIM (N-258,000)** | | **Pop. Based Household Survey (N-8120)** | |
| | **n** | **Prev/1,000 Children** | **n** | **Prev/1,000 Children** |
| Physical | 1,601 | 6.2 [5.9 – 6.5] | 65 | 8.0 [6.1 – 9.9] |
| Bilateral VI | 184 | 0.7 [0.6 – 0.8] | 4 | 0.5 [0.01 – 1.0] |
| Bilateral HI | 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. HI) | 1,937 | 7.5 [7.2 – 7.8] | 61 | 8.4 [6.4 – 10.4] |
| Washington Group (5 Q) [20] | 2417 | 8.3 [8.0-8.7] | 62 | 7.6 [5.7-9.5] |

### Table 42: Bangladesh Gender Ratios

| **Bangladesh Gender Ratios** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **KI Listed** | | **KI Examined** | | **KI Examined – Study Positives** | | **Household Survey – Examined** | | **Household Survey – Study Positives** | |
| | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| Male | 2,194 | 56.0 | 2,096 | 56.4 | 1,356 | 58.1 | 4,120 | 50.7 | 66 | 55.5 |
| Female | 1,724 | 44.0 | 1,623 | 43.6 | 978 | 41.9 | 4,000 | 49.3 | 53 | 44.5 |
| **Total** | **3,918** | **100** | **3,719** | **100** | **2,334** | **58.1** | **8,120** | **100** | **119** | **100** |

Table 42 references the number of children examined in each cohort disaggregated by gender, alongside those screening positive as per the study criteria. In both the KI method and the Household Survey, more male children (58.1% and 55.5% respectively) screened positive as per the study criteria, despite there being an even gender ratio in both. This finding implies a greater proportion of male children than female children with disabilities in the population, not explained by any sampling bias.

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[19] A 95% Confidence Interval is a statistical statement that based on our sample, we are 95% that the true figure in the population lies within this range.

[20] As per the Washington Group definition of at least *A lot of difficulty* in at least *one* of the six domains **or** at least *Some difficulty* in *two or more domains*.

## Household Survey Demographics

Parental literacy rates within the Household Survey were comparable between children with and without targeted impairments or epilepsy (Figure 34). Monthly Family Income (Figure 35) was more evenly spread in the Household Survey than in the KIM (see KIM demographic results on page 32 for comparison of the demographic characteristics both of the Household Survey cohort and the KIM cohort).

**Figure 34: Household Survey Demographic Characteristics – Paternal and Maternal Literacy**

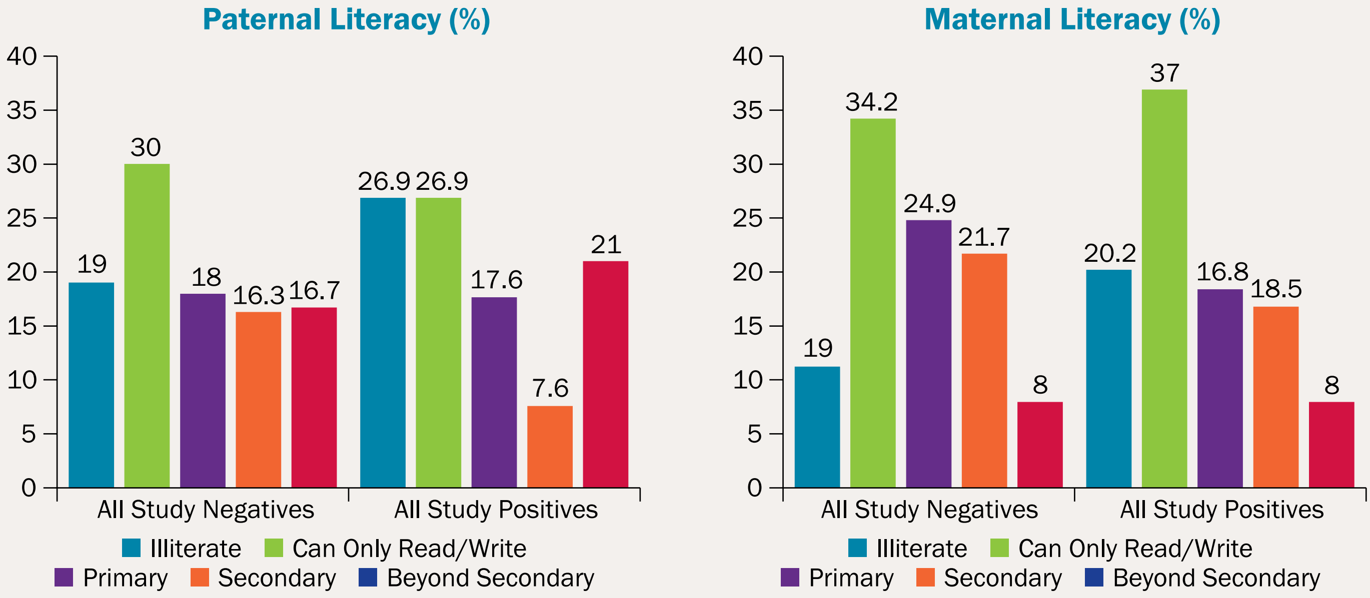
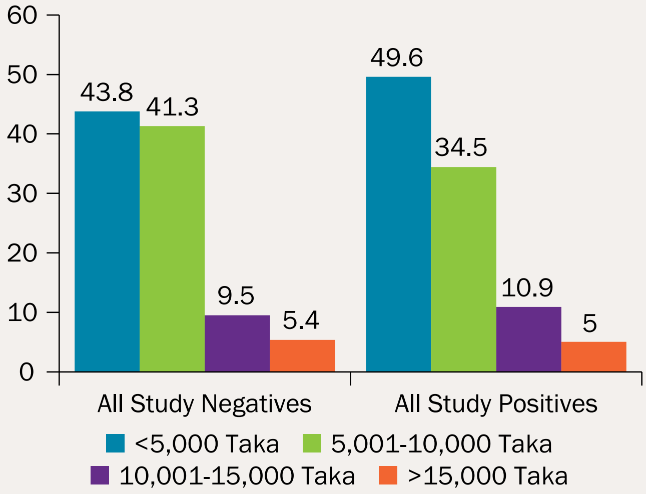


**Figure 35: Household Survey Demographic Characteristics – Monthly Family Income (%)**



## Washington Group Parent Report on Disability Prevalence

**Table 43: Household Survey Reported Degree of Difficulty Using WG Criteria**

| **Concordance between WG and Clinical Diagnosis (%)** | | | | | | |
|---|---|---|---|---|---|---|
| | | **Household Clinical Diagnosis** | | | | |
| | | **Visual Impairment** | **Hearing Impairment** | **Physical Impairment** | **All Study Positives** | **All Other Children** |
| Washington Group Parent Report Domain | Vision | 75.0 | 1.9 | 4.6 | 4.2 | 0.39 |
| | Hearing | 25.0 | 19.2 | 9.2 | 12.6 | 0.81 |
| | Mobility | 50.0 | 1.9 | 35.4 | 20.2 | 0.32 |
| | Communication | 25.0 | 13.5 | 35.4 | 24.4 | 0.61 |
| | Self Care | 50.0 | 3.8 | 33.8 | 20.2 | 0.17 |
| Screen Positive for disability[21] | | 50.0 | 11.5 | 43.1 | 28.6 | 0.35 |

Parental Report of disability as per the Washington Group Questions led to 62 children in the cohort (0.8% of the cohort) screening positive for disability. Of these, 34 (54.8% of children screening positive as per the WG functional domain criteria) were children who also screened positive via clinical diagnosis for the targeted impairments or epilepsy, whilst 28 did not meet the study criteria. Amongst all children who screened positive for the study criteria via clinical diagnosis (n=119), 28.6% also screened positive as per the parental report of disability (Table 43).

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[21] As per the Washington Group definition of at least *A lot of difficulty* in at least *one* of the six domains **or** at least *Some difficulty* in *two or more domains*.

## Education

91% of children who did not meet the study criteria and 62% of children with one of the targeted impairments or epilepsy in the Household Survey over the age of 5 were enrolled in education (Table 44 and Figure 36). The number of Study Positives in education is significantly higher than Study Positives identified via KIs. No children in the Household Survey attended a special school.

Both caregivers of children with and without targeted impairments or epilepsy who were not in school stated a lack of money as the main reason, whilst children without the targeted physical or sensory impairments and/or epilepsy were more likely to be working, whilst children meeting the inclusion criteria faced discrimination in terms of non-acceptance in the school because of their disability (Figure 37).

**Table 44: Household Survey Access to Education**

| Household Survey – Access to Education | | |
|---|---|---|
| | **All Other Children (%)** | **All Study Positives (%)** |
| In school | 90.7 | 61.8 |
| Not in school | 9.3 | 38.2 |
| **Total (n)** | **5,183** | **76** |

**Figure 36: Household Survey Educational Status (% of Children in Survey)**

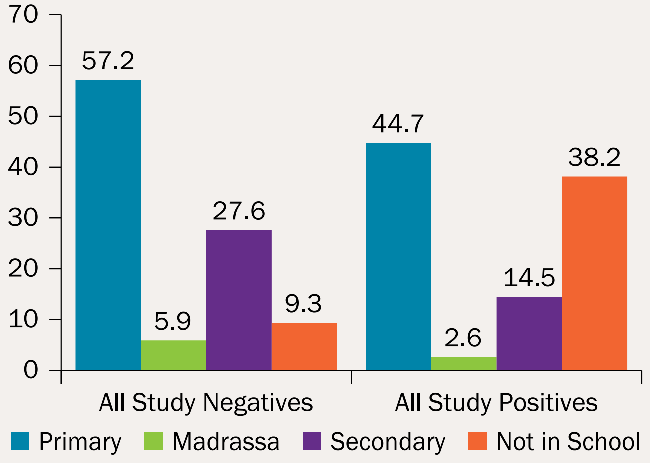
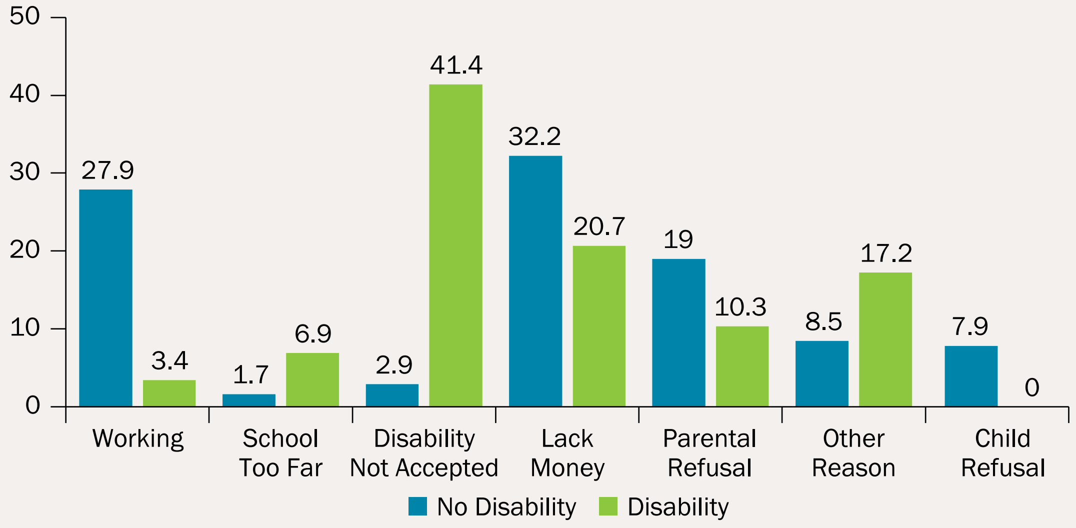


**Figure 37: Household Survey – Reasons not in School (% of Group)**



# KIM Project Costs versus Household Survey Project Costs

**Costs for the key components of using both the Key Informant Method and a traditional Household Survey methodology to identify children with the targeted impairments and health conditions in Bangladesh are outlined below. The total population covered using each method (see Methods section) differed, so the costs below reflect the costs per million total population.**

**Table A: Bangladesh Project Costs**

| Bangladesh Project Costs – Comparison Between KIM and Household Survey Methodology | | |
|---|---|---|
| **Key Project Cost Components** | **Costs to Screen a Total Population of 1 Million** | |
| | **KIM** | **Household Survey** |
| *Salary Costs* | £70,932 | £773,527 |
| *Office Costs* | £24,573 | £267,969 |
| *Field Costs* | £13,025 | £142,036 |
| *Medical Team Costs* | £37,793 | £986,514 |
| *Treatment Costs for Children* | £80,914 | £392,168 |
| *Travel Costs for Children* | £5,250 | £25,445 |
| *Key Informant Training* | £10,976 | N/A |
| *Workshop Costs (Staff Training, Stakeholder Meetings etc.)* | £2,071 | £22,585 |
| **TOTAL COST** | **£245,534** | **£2,610,244** |
| **TOTAL COST – Excluding Treatment and Travel Costs for Children** | **£159,370** | **£2,192,631** |

Costs are shown in Table A both with and without treatment and transport costs for children, to reflect the costs of methods separately from intervention. Costs are estimated based on the proportion of the budget and resources utilised in undertaking both the KIM and the Household Survey in relation to the total population covered by each method. Costs for undertaking a Household Survey are over ten times greater than undertaking a KIM in a population of the same size. This is predominantly because the KIM relies on Key Informants to identify all children targeted in the study directly, without having to screen all children residing in the study area for the target criteria.

Table B clarifies this further, by using the figures from the project to estimate the number of children that would need to be examined and would consequently be identified using both methods in a total population of 1,000,000 (child population estimated at 413,000). Far greater numbers of children would need to be examined using the Household Survey, although more children would also be identified. This can be explained as a result of problems described in the field testing of hearing impairment in the KIM Camps. Table B also shows the cost per child covered, examined diagnosed and referred using both methods. Again, costs are estimated both inclusive and exclusive of costs of treatment and travel to treatment sites.

**Table B: Bangladesh Projects Costs per Child**

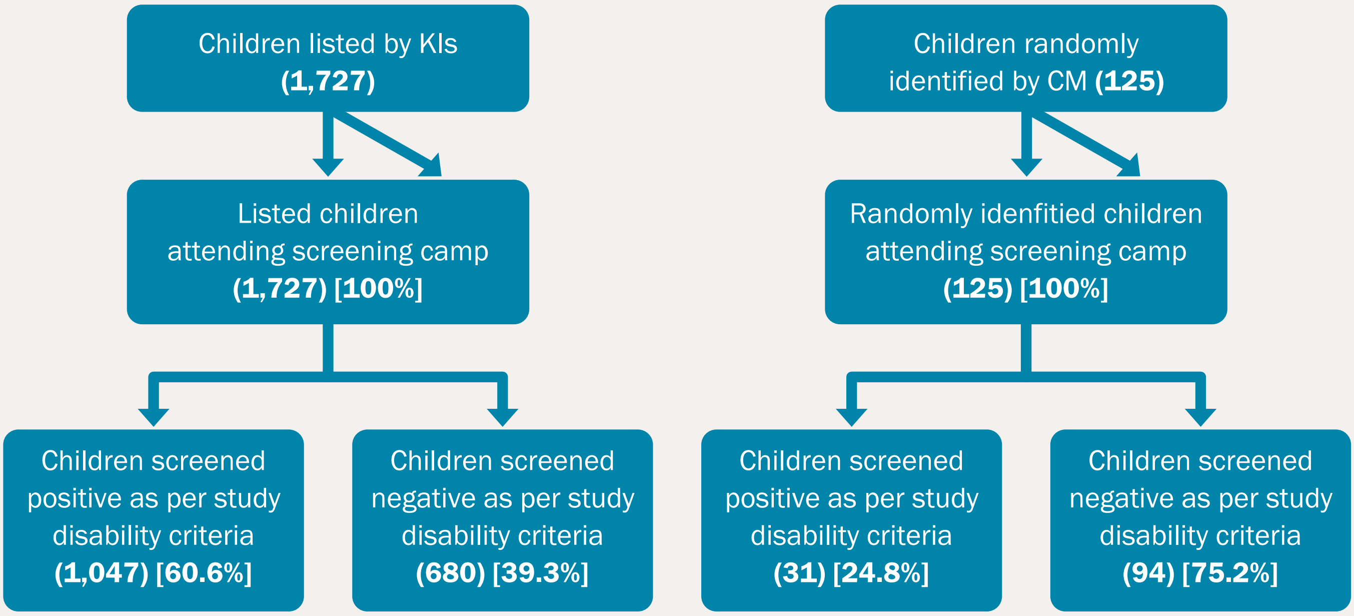
| **Bangladesh Costs per Child** | | |
|---|---|---|
| | **KIM** | **Household Survey** |
| Total Child Population Covered | 413,000 | 413,000 |
| Total No. Children Examined | 6,198 | 413,000 |
| Total No. Children Identified | 3,890 | 6,056 |
| Total Cost per Child Covered | £ 0.57 | £5.76 |
| Total Cost per Child Diagnosed | £63.12 | £431.02 |
| Total Cost per Child Referred | £108.24 | £1,306.12 |
| ***Excluding Treatment and Travel Costs for Children*** | | |
| Total Cost per Child Covered | £0.37 | £4.84 |
| Total Cost per Child Diagnosed | £40.97 | £362.06 |
| Total Cost per Child Referred | £70.26 | £1.097.15 |

# Results: KIM in Pakistan

**Security issues within Pakistan external to the project team created substantial delay and disruption to project activities and reporting. This unfortunately led to limitations in the quality of quantity of data collected. A total of 539 Pakistani KIs (22% female) identified 1,727 children, all of whom were screened at KIM Camps, alongside 125 Non KI Listed children screened for comparison (Figure 38). Limitations in data collection and inconsistencies within the data mean that basic descriptive statistics only are available for Pakistan, and the data is not considered comparable at the national or international level.**

## Response Rates

**Figure 38: Response Rates**



## Descriptives and Sensitivity/Specificity

The gender ratio of KI Listed and Non KI Listed children in Pakistan was not even, with male children accounting for 58.3% of KI Listed and 66.4% of Non KI Listed children in the study (Table 45). 58.6% of the KI Listed cohort and 62.4% of the Non KI Listed cohort were aged ten or younger.

### Table 45: Pakistan – Cohort Descriptives

| Cohort Descriptives – Age and Gender | | | | | | |
|---|---|---|---|---|---|---|
| | | **Age (% cohort)** | | | | **Total % (n)** |
| | | **<=5** | **6-10** | **11-15** | **16-18** | |
| KI Listed | Male | 16.4% | 19.0% | 14.3% | 8.6% | 58.3% (1,007) |
| | Female | 10.9% | 12.3% | 12.3% | 6.1% | 41.7% (719) |
| | **Total** | **27.3% (471)** | **31.3% (541)** | **26.6% (459)** | **14.8% (255)** | **100% (1,726)** |
| Non KI Listed | Male | 31.2% | 15.2% | 12.8% | 7.2% | 66.4% (83) |
| | Female | 10.4% | 5.6% | 8% | 9.6% | 33.6% (42) |
| | **Total % (n)** | **41.6% (52)** | **20.8% (26)** | **20.8% (26)** | **16.8% (21)** | **100% (125)** |

### Table 46: Pakistan – Number of Children Screened by KI

| Cohort Descriptives – Disability | | | |
|---|---|---|---|
| **Group** | **Screen Positive for severe disability** | **Screen Negative for severe disability** | **Total** |
| KI Listed | 60.6% (1,047) | 39.4% (680) | 100% (1,727) |
| Non KI Listed | 24.8% (31) | 75.2% (94) | 100% (125) |

60.6% of the KI Listed cohort screened positive for moderate or worse physical or sensory impairments, or epilepsy through clinical examination (Table 46). Table 47 shows that, similarly to the Bangladesh cohort, sensitivity was very high at 97.1% but specificity was even lower than in Bangladesh (12.1%).

### Table 47: Pakistan – Validity of Method

| Cohort Descriptives – Sensitivity/Specificity | |
|---|---|
| Sensitivity (%) | 97.1 |
| Specificity (%) | 12.1 |
| Positive Predictive Value (%) | 60.6 |
| Negative Predictive Value (%) | 75.2 |
| Correctly Classified (%) | 61.61 |

Almost a quarter of Non KI Listed children (24.8%, see Table 46) screened positive as per the study criteria, suggesting that KIs were not efficient at identifying all children matching the targeted study criteria in their communities. This may have been for one of several reasons – the KI's may not have performed effectively (whether due to training or to difficulties in undertaking the KI role within the national political context), the Non KI Listed children may not have been selected randomly or the incidence of the targeted conditions in Pakistan may be very high.

Amongst the KI Listed cohort who screened negative for the study criteria, most had mild/moderate impairments, non targeted impairments or chronic health conditions/ other morbidities. Full information on these morbidities or impairments is unfortunately not available.

## Prevalence

Table 48 lists the number of children identified in the study meeting the target criteria. Using population data, estimates of prevalence per 1,000 children have been included. 5.4 children per 1,000 children screened positive for the targeted impairments or epilepsy. The estimates are much lower than in Bangladesh, which may signify less children with the targeted impairments or health conditions in Pakistan, that Key Informants were less effective in Pakistan or that problems with the data have skewed the findings in Pakistan.

**Table 48: Pakistan – Prevalence and National Magnitude of Targeted Impairments/Health Conditions**

| **Child Disability Prevalence – Clinical Screening** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | **n (Study)** | **Prev/ 1,000 children**[22] | **95% CI**[23] | | **Prev/ million total population** | **95% CI** | | **National Magnitude (Child)**[24] |
| Moderate or Worse Impairment | Physical | 759 | 3.9 | 3.62 | 4.17 | 1,636 | 1,520 | 1,753 | 251,138 |
| | Visual | 48 | 0.2 | 0.18 | 0.32 | 103 | 74 | 133 | 15,882 |
| | Hearing[i] | 237 | 1.2 | 1.06 | 1.37 | 511 | 446 | 576 | 78,419 |
| Health Condition | Epilepsy | 153 | 0.8 | 0.66 | 0.91 | 330 | 278 | 382 | 50,625 |
| | CP | 430 | 2.2 | 2.00 | 2.42 | 927 | 840 | 1015 | 142,278 |
| Study Positives (One or more of the above) | | 1,049 | 5.4 | 5.06 | 5.71 | 2262 | 2,125 | 2,398 | 347,093 |

[i] Unlike in Bangladesh, the Pakistan team did not report field problems in screening for hearing impairment using PTA or OAE so all hearing impairment here is confirmed.

## Washington Group Parent Report on Disability (5 Questions)

742 children in the Pakistan cohort, equating to 3.8/1,000 children, screened positive for disability as per parent-report using the Washington Group Questions. Table 49 outlines the percentage of Study Positives in the sample responding that they had some difficulty, a lot of difficulty or an inability at all in performing each of the five core functioning domains. Respondents reported the most difficulties in mobility and communication, with 26.3% and 32.8% respectively either experiencing a lot of difficulty or an inability to perform the activity at all.

**Table 49: Pakistan – Reported Degree of Difficulty using WG Criteria**

| **Washington Group Questions – Core Domain Limitations** | | | | |
|---|---|---|---|---|
| | **Degree of Difficulty (% Study Positives in Sample)** | | | |
| **Core Domains** | **No Difficulty** | **At least some difficulty** | **At least a lot of difficulty** | **Unable to do it at all** |
| Vision | 90.9 | 3.7 | 2.1 | 3.3 |
| Hearing | 70.7 | 5.5 | 5.4 | 18.4 |
| Mobility | 65.6 | 8.1 | 8.0 | 18.3 |
| Communication | 59.9 | 7.3 | 6.6 | 26.2 |
| Self Care | 72.2 | 7.1 | 6.5 | 14.2 |

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[22] Prevalence estimated using BIPR and 1998 Pakistan Census Data on district population and national population <18.

[23] National Magnitude taken from census total population est. 132,352,000. Child popn ~ 42%.

[24] Assumes validity of method (see page 60 for validation).

**Table 50: Pakistan – Concordance Between WG Criteria and Clinical Diagnosis**

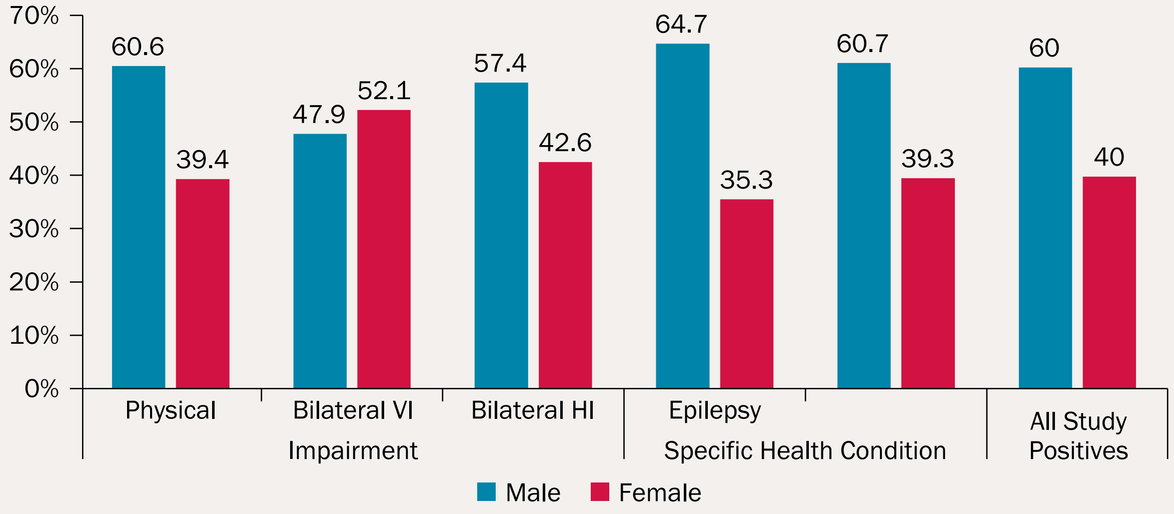
| Concordance between WG and Clinical Diagnosis (%) | | | | |
|---|---|---|---|---|
| | | **Clinical Diagnosis** | | |
| | | **Visual Impairment** | **Hearing Impairment** | **Physical Impairment** |
| Washington Group Parent Report Domain | Vision | 64.6 | 6.8 | 8.4 |
| | Hearing | 16.7 | 81.0 | 18.2 |
| | Mobility | 41.7 | 13.9 | 43.1 |
| | Communication | 31.3 | 65.4 | 36.5 |
| | Self Care | 50.0 | 10.5 | 34.5 |
| Screen Positive for Disability[25] | | 79.2 | 82.3 | 53.5 |

Table 50 shows concordance between specific core domains and clinically diagnosed moderate or worse impairments. The numbers signify the percentage of children with each clinically diagnosed targeted physical or sensory impairment reported to have either some problem, a lot of problem or an inability to carry out each of the core function domains. Numbers in bold signify the concordance between each clinically diagnosed impairment type and the related functional domain. The highest concordance was the 81% of respondents stating a hearing problem amongst children clinically diagnosed hearing impairments, whilst only 43.1% of respondents reported that children with significant physical impairments had a problem with mobility.

## Demographic Characteristics of Children Attending KIM Camps

More male children were diagnosed with moderate or severe impairments or epilepsy across the entire cohort (60% male, 40% female), although this was reversed amongst children with visual impairment (52.1% female – see Figure 39). The most pronounced gender difference was amongst children with epilepsy (64.7% male).

**Figure 39: Pakistan – Demographic Characteristics of Children Attending KIM Camps – Gender (% Cohort)**



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[25] As per the Washington Group definition of at least *A lot of difficulty* in at least *one* of the six domains **or** at least *Some difficulty* in *two or more domains*.

**Figure 40: Pakistan – Demographic Characteristics of Children Attending KIM Camps – Age Group (%)**

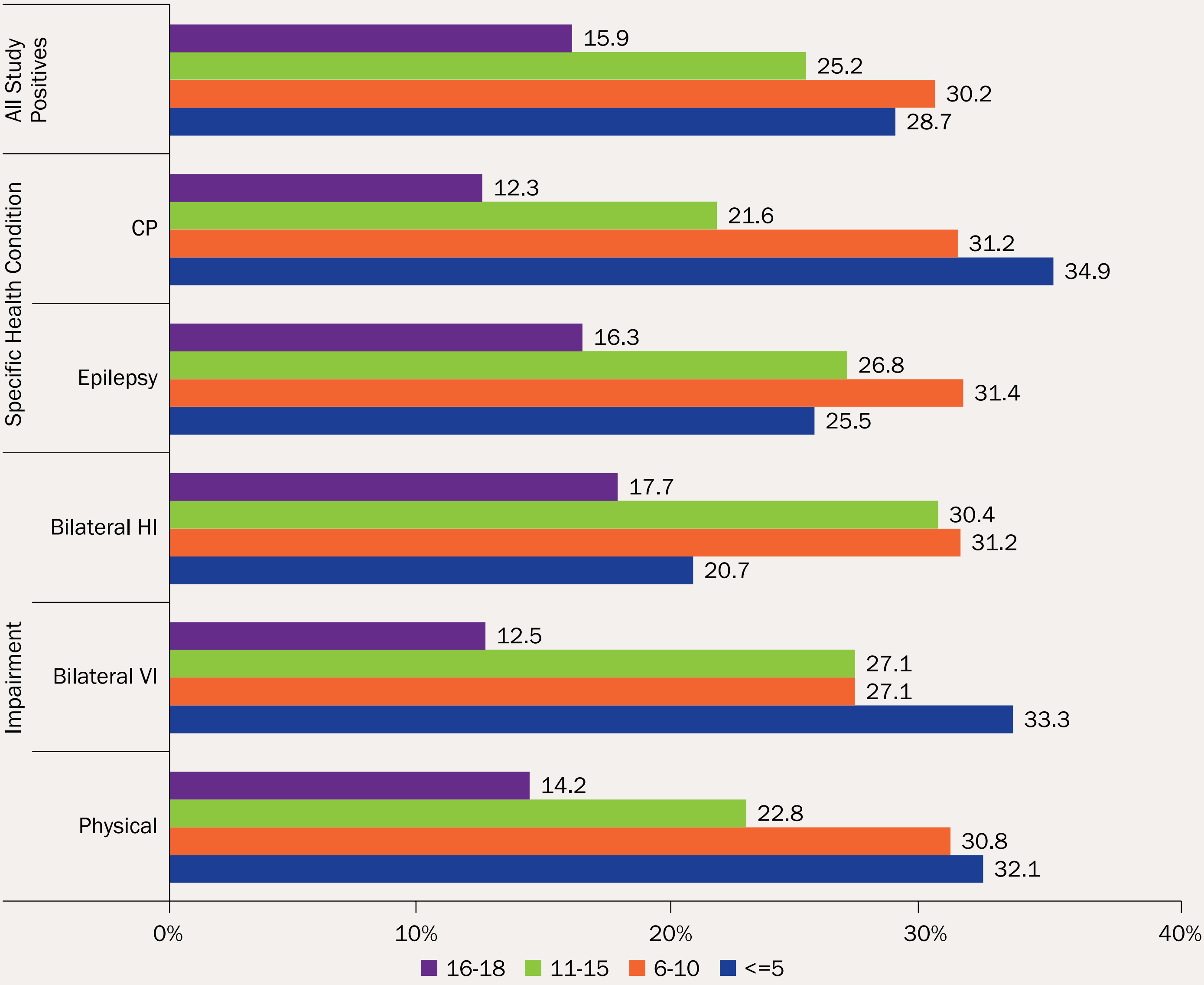

Figure 40 gives age-disaggregated information about Study Positives. Similarly to the age distribution amongst the total cohort identified and listed by KIs, 58.9% of children diagnosed with moderate or worse impairments or epilepsy in the cohort were under the age of 11. Children diagnosed with Cerebral Palsy were the most likely to be aged less than 11 (66%).

Figures 41-42 (pages 71 and 72) outline further demographics of the cohort of Study Positives in relation to the Non KI Listed children screened for comparison. Parents of children screening positive for the study criteria reported slightly higher maternal and paternal literacy rates than the Non KI Listed cohort (Figure 41). The minority of parents of both Study Positives and Non KI Listed children had not had any form of education.

The greater number of respondents stated their monthly family income to be in the second lowest income bracket (5,001-10,000 Rupees) in both the study positive and Non KI Listed cohort[26]. 9.3% of the study positive cohort and 11.2% of the Non KI Listed cohort were in either of the higher two income brackets (>10,001 Rupees per month).

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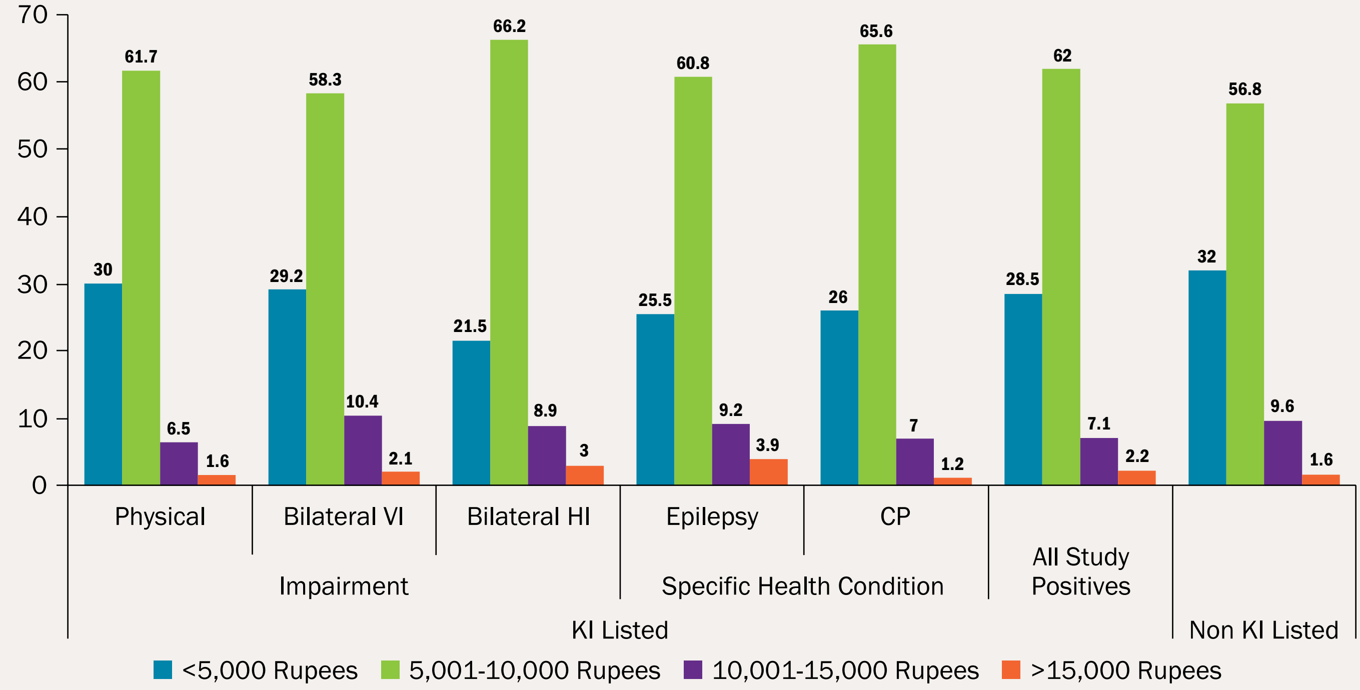
[26] 5,001-10,000 Rupees is roughly equivalent to between £33-£65 or €37-€75.

**Figure 41: Pakistan – Demographic Characteristics of Children Attending KIM Camps**

**Figure 42: Pakistan – Demographic Characteristics of Children Attending KIM Camps – Monthly Family Income (% Cohort)**



## Target Impairment and Health Condition Diagnoses

Significant physical impairment was the most commonly diagnosed amongst the targeted impairments and health conditions of the study, accounting for 81% of all Study Positives in the Pakistan cohort. Table 51 enumerates the underlying causes diagnosed amongst all children with significant physical impairments (n=850) in the study.

**Table 51: Pakistan – Physical Impairments**

| Cause of significant physical impairment[27] | n (study) | % children with significant physical impairment | Prev/1,000 children | Prev/million population |
|---|---|---|---|---|
| Cerebral Palsy | 430 | 50.6 | 2.2 | 927 |
| Club Foot | 59 | 6.9 | 0.3 | 127 |
| Other Type Congenital | 64 | 7.5 | 0.3 | 138 |
| Muscular Dystrophy | 56 | 6.6 | 0.3 | 121 |
| Cleft Lip/Palate | 20 | 2.4 | 0.1 | 43 |
| Genetic | 20 | 2.4 | 0.1 | 43 |
| Trauma/Burn | 15 | 1.8 | 0.1 | 32 |
| Hydrocephalus | 26 | 3.1 | 0.1 | 56 |
| Polio | 65 | 7.6 | 0.3 | 140 |
| Spina Bifida | 10 | 1.2 | 0.1 | 22 |
| Amputee | 8 | 0.9 | 0.0 | 17 |
| Spinal Cord Injury | 7 | 0.8 | 0.0 | 15 |
| Rickets | 11 | 1.3 | 0.1 | 24 |
| Others | 59 | 6.9 | 0.3 | 127 |
| **Total** | **850** | **100.0** | **4.3** | **1,832** |

Cerebral Palsy was by far the most common cause diagnosed (51% of children with physical impairments), followed by polio (7.6% of children with physical impairments) and undisclosed congenital conditions (7.5%).

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[27] Note as mentioned previously, these are according to strict project criteria and causing significant loss of functioning. These numbers do not include children with health conditions causing mild/moderate impairment to physical functioning.

Cerebral Palsy was the single most diagnosed condition in the Pakistan cohort, with 430 children identified with significant physical impairment attributed to CP (41% of all children screening positive for targeted impairments or epilepsy in the Pakistan study). Similar to the figures for Bangladesh (see page 35), approximately 25% of children identified with Cerebral Palsy in Pakistan also screened positive for sensory impairments or epilepsy (Table 52). 5.7% of children meeting the target criteria in the study (n=30) had multiple impairments that were not related to Cerebral Palsy pathology (Table 53).

### Table 52: Pakistan – Cerebral Palsy Pathology

| Multiple Impairments Pathology | | |
|---|---|---|
| **(Excludes Children with Cerebral Palsy)** | **n (Study)** | **% Children With Disabilities** |
| Epilepsy with Bilateral HI | 1 | 0.1 |
| Epilepsy with Bilateral VI | 0 | 0.0 |
| Physical with Epilepsy | 5 | 0.5 |
| Physical with Epilepsy and Bilateral HI | 1 | 0.1 |
| Physical with Epilepsy, Bilateral VI and Bilateral HI | 1 | 0.1 |
| Physical with Bilateral HI | 14 | 1.3 |
| Physical with Bilateral VI | 7 | 0.7 |
| Bilateral VI with Bilateral HI | 1 | 0.1 |
| **Total** | **30** | **2.9** |

### Table 53: Pakistan – Multiple Impairment Pathology

| CP Pathology | | |
|---|---|---|
| **CP Pathology** | **n (Study)** | **% Children With CP** |
| CP – no other presentations | 324 | 75.3 |
| CP & Epilepsy | 68 | 15.8 |
| CP & Bilateral HI | 21 | 4.9 |
| CP & Bilateral VI | 9 | 2.1 |
| CP & Epilepsy & Bilateral HI | 6 | 1.4 |
| CP & Epilepsy & Bilateral VI | 1 | 0.2 |
| CP & Bilateral HI & Bilateral VI | 0 | 0.0 |
| CP & Epilepsy & Bilateral HI & Bilateral VI | 1 | 0.2 |
| **Total** | **430** | **100.0** |

## Parental Perception and Clinical Diagnosis

As in Bangladesh, children with physical impairments were most likely to have acquired their impairments at birth, whilst caregivers generally perceived visual impairments, hearing impairments and epilepsy to have been acquired later in childhood. 61.1% of caregivers did not know the cause of the child's impairment or health condition, with delayed crying perceived by 22.6% of respondents as the apparent cause of the child's moderate or worse impairment, or epilepsy (Figure 43 and Figure 44). Cerebral Palsy, given its attribution for such a large proportion of the cohort of Study Positives, is shown separately in the figures, but is the underlying health condition diagnosed as causing significant physical impairment in 56.7% of all physical impairment diagnoses.

**Figure 43: Pakistan – Reported Onset at Birth (% Cohort)**

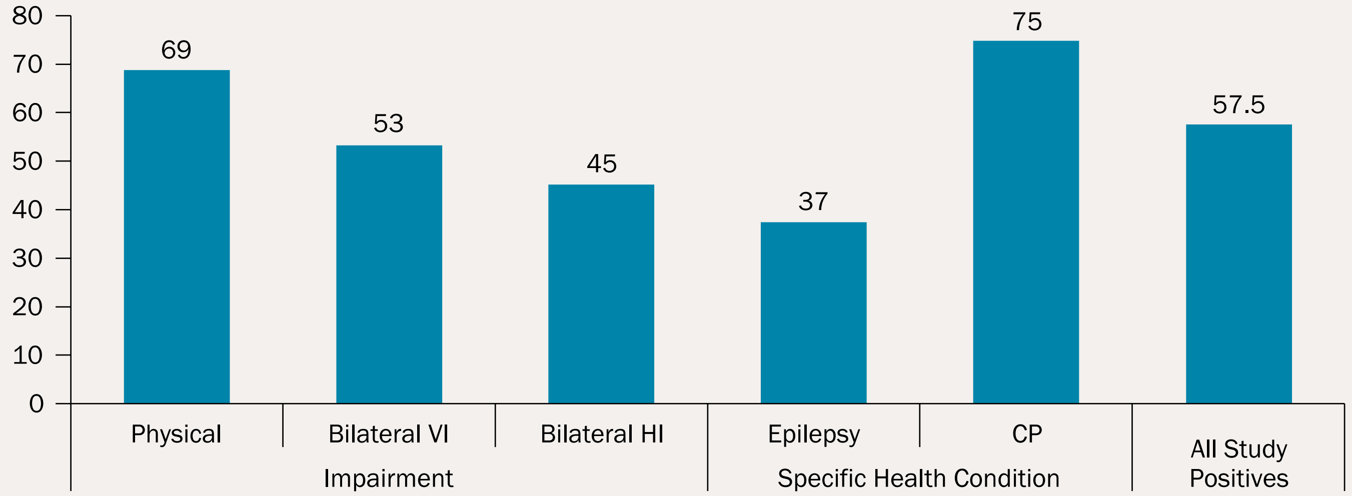


**Figure 44: Pakistan – Apparent Cause (% Cohort)**

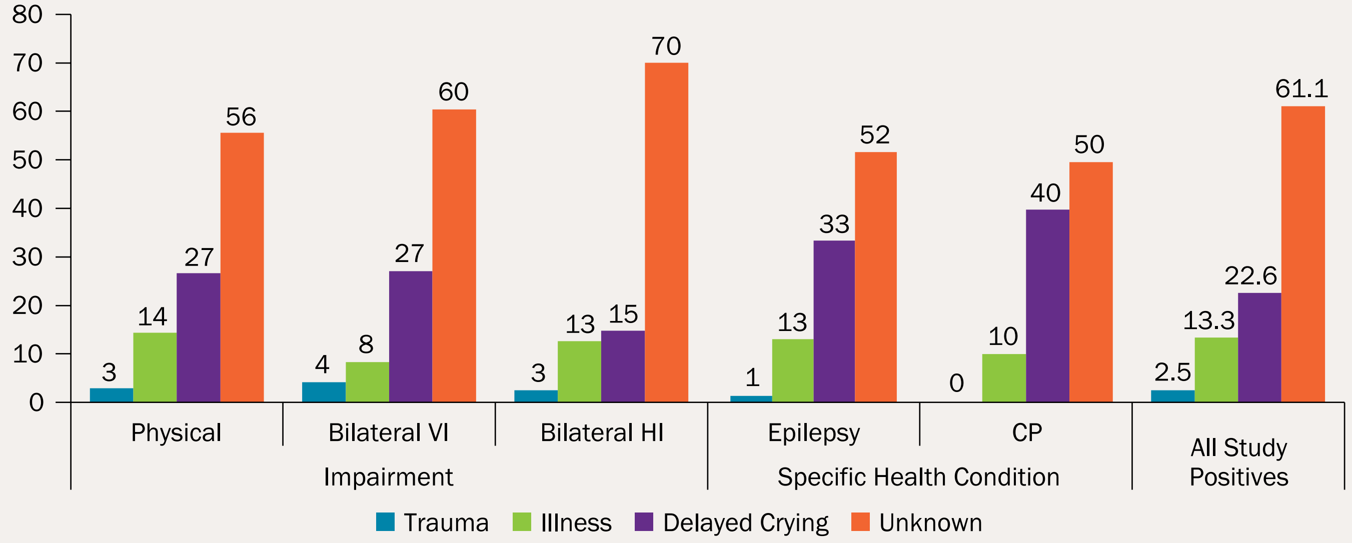


**Table 54: Parental Cosanguinuity (% Cohort)**

| Parent Consanguinity (% Cohort) | | | | | | |
|---|---|---|---|---|---|---|
| **KI Listed** | | | | | | **Non KI Listed** |
| Impairment | | | Specific Health Condition | | All Study Positives | |
| Physical | Bilateral VI | Bilateral HI | Epilepsy | CP | | |
| 44.1 | 58.3 | 44.7 | 41.8 | 43.5 | 45.0 | 19.2 |

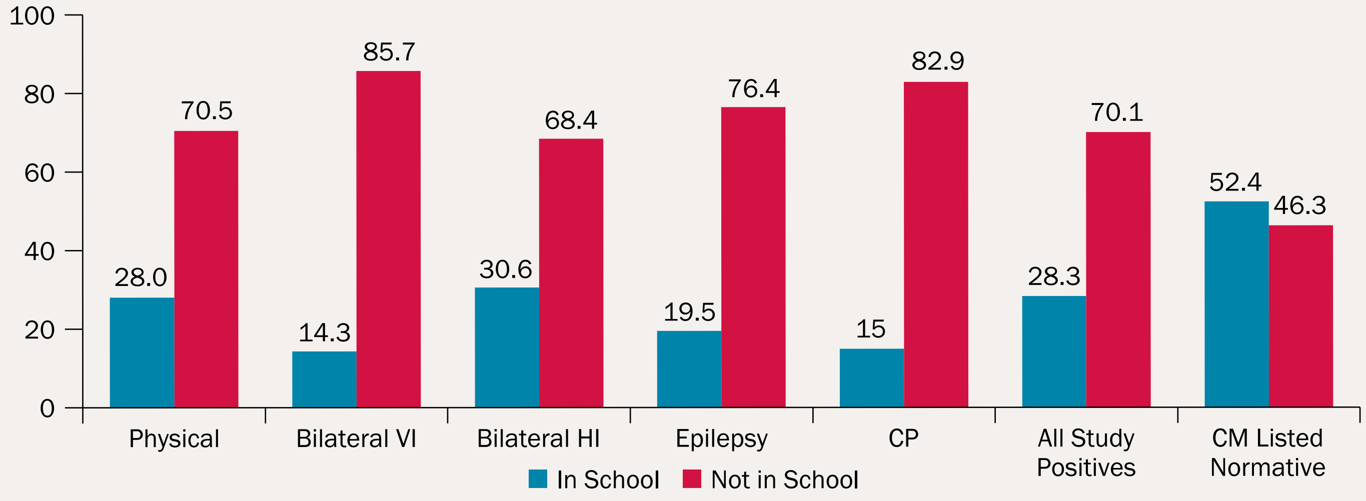
Consanguinity amongst parents of children with targeted moderate or worse impairments or epilepsy in the sample was almost double that of Non KI Listed children screened for comparison (44.1% versus 19.2% of parents – see Table 54). Consanguinity has been shown to increase the likelihood of developing learning or sensory impairments through the impact on the child's genetics [45].

Less than 2% (n=17) of study positive respondents stated that the mother had been taking strong medicine whilst pregnant with the child, whilst 7.6% (n=80) stated that the parents or relatives of the child had the same impairment or health condition – suggesting a potential hereditary link.

## Education

Figure 45 (below) and Table 55 on page 77) show the educational status of school-aged children (aged five and older) enrolled in any type of education in Pakistan. Children with Cerebral Palsy or visual impairment were the least likely to be in school (15% and 14.3% of the respective school-aged visual impairment and CP cohorts), with 27.6% of all children meeting the study target criteria overall in school, compared with 52.4% of Non KI Listed children screened for comparison. This implies a significant difference between the numbers of children with and without targeted impairments/health conditions in education in Pakistan.

**Figure 45: Pakistan – Educational Status (%)**

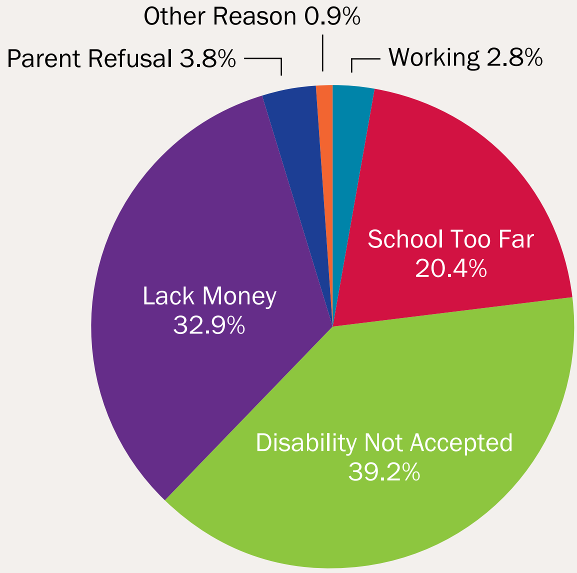


## Table 55: Pakistan – Access to Education

| Access to Education | | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Impairment** | | | **Health Condition** | | **All Study Positives (%)** | **Non KI Listed (%)** |
| | **Physical (%)** | **Bilateral VI (%)** | **Bilateral HI (%)** | **Epilepsy (%)** | **CP (%)** | | |
| Attends School | 28.0 | 14.3 | 30.6 | 19.5 | 15.0 | 28.3 | 52.4 |
| Does not attend school | 70.5 | 85.7 | 68.4 | 76.4 | 82.9 | 70.1 | 46.3 |
| **Total (n)** | **572** | **35** | **206** | **123** | **326** | **824** | **82** |

As in Bangladesh, a lack of money and disability not being accepted by the school were the most common reasons for children meeting the target criteria in the study not attending school (Figure 46). 3.6% of children with targeted impairments or epilepsy in the study (n=30) attended special schools, with almost all (n=27) of these also attending mainstream school.

## Figure 46: Pakistan – Reasons not in School



## Previous Rehabilitation Support

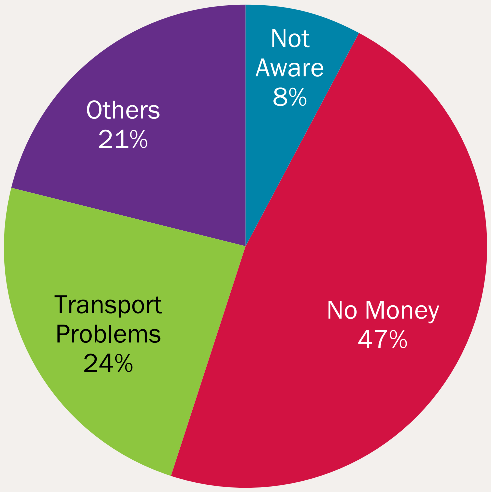
82.7% of children with targeted impairments or epilepsy in the cohort had not previously received rehabilitative support or services (Table 56).

**Table 56: Pakistan – Previous Rehab Received**

| Previous Rehabilitative Support/Services Received (% Group)[28] | | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Any Prior Rehab** | **Assistive Device** | **Surgery** | **Therapy Exercises** | **Advice** | **Other** | **No Prior Rehab** |
| Physical | 29.2 | 2.2 | 2.9 | 4.1 | 9.1 | 0.7 | 70.8 |
| Visual | 15.7 | 2.1 | 4.2 | 10.4 | 18.8 | 0.0 | 84.3 |
| Hearing | 14.4 | 3.4 | 0.8 | 2.5 | 8.0 | 0.4 | 85.6 |
| Epilepsy | 17.4 | 2.6 | 0.7 | 3.3 | 9.8 | 1.3 | 82.6 |
| CP | 16.0 | 1.9 | 0.7 | 3.7 | 8.6 | 0.2 | 84.0 |
| All Study Positives | 17.3 | 2.7 | 2.4 | 3.6 | 9.2 | 0.7 | 82.7 |

Of those that had, the majority had received advice (9.2%), highlighting the lack of access to appropriate services for the cohort. As in Bangladesh, for those who had never previously received any support or service, the majority could not to do so (47% of reasons cited – see Figure 47). However, unlike Bangladesh, problems with transport were a significant issue cited by 24% of respondents – potentially due to the greater distances between the study participants and appropriate services, or greater complications in physically accessing services.

**Figure 47: Pakistan – Reasons no Rehab Received**



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[28] Type of service previously received may be greater than 1.

# Barriers – A Summary

**The following is a summarised account of the work of Dr. Juliet Bedford and Ms. Robin Nesbitt on Barriers and predictors of referral uptake amongst the cohort. For full papers, please refer to the abstracts on page 100.**

## Children with Disabilities in Bangladesh: A Mixed Methods Approach to Barriers and Predictors of Referral Uptake

**Robin Nesbitt (LSHTM) and Dr. Juliet Bedford (Director, Anthrologica)**

### Purpose

To undertake a mixed-methods sub-study within the KIM child disability study to answer the following key qualitative and quantitative questions:

### Qualitative

Why do children not take up referrals offered by the project? What are the barriers preventing uptake?

### Quantitative

Who is not taking up referrals and what are the predictors of referral uptake?

**Photo 10: Child with uncorrected Club Foot**

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### Introduction

Here we present results from a study conducted in Bangladesh on the barriers to and predictors of referral uptake for children with disabilities identified through the Key Informant Methodology. Adopting a pragmatic approach to mixed methods research, we use results from qualitative work on barriers to referral uptake to interpret results from quantitative work on predictors of referral uptake.

### Methods

This analysis is undertaken based on the referral logs of 1,911 children from Sirajganj and Natore, Bangladesh, classified as meeting the inclusion criteria for targeted moderate or worse physical or sensory impairments, or epilepsy in the KIM Child Disability Project. Of those, 1,308 (68%) were given referrals for rehabilitative or medical services, or for further investigation (612 from Sirajganj and 696 from Natore).

Children with referrals were prospectively traced between six and eighteen months after their attendance at a screening camp. In both districts, 48% of children who received referrals acted on them after their attendance at a screening camp. In Sirajganj, 212 children (33%) followed up with their referral and 424 children (61%) in Natore.

Univariate and multivariate quantitative analyses were undertaken to identify demand-side predictors of referral uptake using logistic regression, separately and for both districts combined[29]. In-depth interviews were conducted in November and December of 2010 with 51 children who did not take up referrals to explore reasons for non-uptake.

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[29] Univariate analysis refers to the relationship between a single variable (e.g. income levels) on the outcome (uptake of services). Multivariate analysis accounts for the impact of more than one variable (e.g. income level and age of child) on the outcome so as to be able to adjust accordingly.

## Results

Within both districts, the children were similarly distributed by age group; approximately 40% were between 6-12 years old, and about a quarter of the children were adolescents (Table 57). In both districts more boys were brought to the camps than girls, but there were more female children attending camps in Sirajganj than in Natore, and there were more children from rural areas, from families of low income, and with illiterate mothers in Sirajganj than in Natore.

### Table 57: Cohort Characteristics

| Characteristics | | | | |
|---|---|---|---|---|
| **Characteristic** | | **Sirajganj n (%)** | **Natore n (%)** | **P-Value** |
| Age Group | Infant (0-23 mo) | 50 (8.2) | 44 (6.3) | 0.533 |
| | Preschool (2-5 yrs) | 160 (26.0) | 176 (25.3) | |
| | Child (6-12 yrs) | 245 (40.0) | 283 (40.7) | |
| | Adolescent (13-18 yrs) | 157 (25.6) | 193 (27.7) | |
| Gender | Male | 345 (56.4) | 438 (62.9) | 0.016 |
| | Female | 267 (43.6) | 258 (37.1) | |
| Residence | Rural | 560 (91.5) | 494 (71.0) | <0.001 |
| | Urban | 52 (8.5) | 202 (29.0) | |
| Monthly Income | <5,000 Taka | 245 (91.8) | 474 (68.1) | <0.001 |
| | >5,000 Taka | 22 (8.2) | 222 (31.9) | |
| Maternal Literacy | Illiterate | 249 (40.7) | 125 (18.0) | <0.001 |
| | Literate | 363 (59.3) | 571 (82.0) | |

### Table 58: Cohort Impairment Types

| Impairment Types[30] | | | |
|---|---|---|---|
| | **Sirajganj (n=612)** | **Natore (n=696)** | **P-Value[31]** |
| Physical | 409 (66.8) | 531 (76.3) | <0.001 |
| Epilepsy | 121 (19.8) | 132 (19.0) | 0.713 |
| Visual | 70 (11.4) | 39 (5.6) | <0.001 |
| Hearing | 202 (33.0) | 136 (19.5) | <0.001 |
| Multiple | 147 (24.0) | 124 (17.8) | 0.006 |

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[30] Impairment types are non-mutually exclusive groups.

[31] Chi Square test for difference in proportion of children attending KIM Camp with impairment by district.


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**Photo 11: Bangladeshi girl**

Physical impairment was the most common impairment, present in 67% of children in Sirajganj, and 73% of children in Natore (Table 58 on page 80). Approximately 20% of children in both groups had epilepsy. Visual impairments were the least common in both groups, in 11% of children in Sirajganj and 6% in Natore.

Hearing impairment was more common in Sirajganj at 33% than in Natore at 20%. The impairment groups are non-mutually exclusive; 24% of children in Sirajganj had multiple impairments, and 18% had multiple impairments in Natore.

In Sirajganj factors predictive of uptake in univariable analyses were: urban residence, paternal literacy, monthly income >5,000 Taka, physical impairment, epilepsy, and lack of hearing impairment. In multivariable analysis also adjusted for age, only monthly income, epilepsy and physical impairment were predictive of referral uptake, all increasing the odds of uptake by approximately 2.6 times (Table 59).

In Natore, factors predictive of referral uptake in univariable analyses were: maternal literacy, monthly income, epilepsy, no visual impairment, multiple impairments and a later onset of impairment. In multivariable analyses also adjusted for age, only maternal literacy, epilepsy and no visual impairment remained associated with referral uptake (Table 60 on page 82).

**Table 59: Predictors of Uptake – Sirajganj**

**Predictors of Uptake – Sirajganj**

| Characteristic | | n | Univariable Odds Ratio (OR) (95%Confidence Interval [CI]) | P-Value | Multivariate OR (95% CI) | P-Value |
|---|---|---|---|---|---|---|
| Residence | Rural | 560 | 1.0 | 0.04 | | |
| | Urban | 52 | 1.84 (1.03-3.29) | | | |
| Paternal Literacy | Illiterate | 282 | 1.0 | 0.02 | | |
| | Literate | 330 | 1.53 (1.08-2.17) | | | |
| Monthly Income | <5,000 Taka | 245 | 1.0 | 0.002 | 1.0 | 0.004 |
| | >5,000 Taka | 22 | 2.73 (1.46-5.10) | | 2.62 (1.37-5.00) | |
| Physical Impairment | No | 203 | 1.0 | <0.001 | 1.0 | <0.001 |
| | Yes | 409 | 2.38 (1.58-3.60) | | 2.69 (1.75-4.13) | |
| Epilepsy | No | 491 | 1.0 | <0.001 | 1.0 | <0.001 |
| | Yes | 121 | 2.25 (1.48-3.41) | | 2.61 (1.68-4.03) | |
| Hearing Impairment | No | 410 | 1.0 | 0.001 | | |
| | Yes | 202 | 0.51 (0.35-0.76) | | | |

**Table 60: Predictors of Uptake – Natore**

| Predictors of Uptake – Natori | | | | | | |
|---|---|---|---|---|---|---|
| **Characteristic** | | **n** | **Univariable Odds Ratio (OR) (95%Confidence Interval [CI])** | **P-Value** | **Multivariate OR (95% CI)** | **P-Value** |
| Maternal Literacy | Illiterate | 125 | 1.0 | 0.02 | 1.538 (1.02-2.45) | 0.04 |
| | Literate | 571 | 1.63 (1.09-2.42) | | | |
| Monthly Income | <5,000 Taka | 474 | 1.0 | 0.06 | | |
| | >5,000 Taka | 222 | 1.38 (0.99-1.94) | | | |
| Epilepsy | No | 564 | 1.0 | <0.001 | 1.0 | <0.001 |
| | Yes | 132 | 13.33 (6.39-27.82) | | 13.49 (6.45-28.24) | |
| Visual Impairment | No | 657 | 1.0 | 0.01 | 1.0 | 0.008 |
| | Yes | 39 | 0.41 (0.22-0.82) | | 0.38 (0.18-0.78) | |
| Multiple Impairment | No | 491 | 1.0 | 0.03 | | |
| | Yes | 124 | 1.60 (1.05-2.44) | | | |
| Hearing Impairment | No | 438 | 1.0 | 0.02 | | |
| | Yes | 258 | 1.47 (1.06-2.05) | | | |

## Socioeconomic Status

Monthly income >5,000 Taka was associated with an increased odds of referral uptake of 2.69 (95% CI 1.75-4.13) in Sirajganj, and it was not associated with referral uptake in multivariable analysis in Natore.

A small monetary contribution was asked from families for services if they could afford it in Sirajganj, but not in Natore. Qualitative research revealed that referrals often assumed second place to daily survival for these families, and the child's disability did not have enough socioeconomic priority to follow through with the referral. Many families reported that both direct and indirect costs of referral uptake were prohibitive, even when costs of services were covered.

## Location

In Sirajganj, urban residence increased referral uptake by 1.84 (95% CI 1.03-3.29) in univariable analysis, but was not a predictive of uptake after adjusting for monthly income. However, support for transportation was provided if families needed help reaching their referral, therefore it would seem that residence increased referral uptake through its correlation with higher socioeconomic status. However, families suggested that mobility limitations prevented travel to referrals; that public transport was infeasible; and that mothers would not travel alone to unknown locations to take up referrals with their children. This suggests that more than economic influence, the effect of urban residence signalled the importance of distance to referral as a predictor of uptake.

## Maternal Literacy

In Natore, maternal literacy was associated with an increase in referral uptake of 1.58 (95% CI 1.02-2.45) in multivariable analyses. Monthly income did not remain associated with referral uptake in the multivariable model, and it is possible that maternal literacy better captured socioeconomic differentials in this district. The importance of the influence of other family and community members on the ability to act and make decisions as recounted in the qualitative case studies, suggests that perhaps the influence of maternal literacy is through increased autonomy rather than socioeconomic status.

## Impairment Type: Epilepsy

The presence of epilepsy increased the odds of referral uptake in both Sirajganj (OR 2.61, 95% CI 1.68-4.03) and in Natore (OR 13.46, 95% CI 6.45-28.24). Over 80% of children in both districts were given a first dose of anti-epileptics at the camp and a referral for continuing medication. It is possible that the high referral uptake in these children was due to the acceptability and ease of taking medication.

Indepth interviews with children with epilepsy who did not take up their referrals suggest that this was because of the effect the medication had on their seizures; if the medication reduced the seizures it was seen that there was no need to follow up with the referral, but if the medication did not reduce the seizures, there was no point in following up with the referral. This insight suggests that more communication at the point of referral provision on the effect of anti-epileptic medication and need for long-term usage would encourage uptake.

## Referral Organization/Procedures

Overall the uptake of referrals was almost twice as high in Natore (61%) than in Sirajganj (33%). Sirajganj was the pilot district for the KIM project and camp procedures changed in the second district, Natore. CSF (the implementing partner) covered the complete cost of referrals and arranged transport with each family after noticing the low uptake of referrals. Although we cannot conclude that the changes in study protocol were responsible for the increase in referral uptake, it is likely that this change in protocol helped facilitation referral uptake.

Qualitative research revealed confusion and misunderstanding about the camp process. Parents reported unmet expectations that discouraged referral uptake, and that dissatisfaction with a referral led to deliberate non-uptake. Again this suggests that improvements to the camp process itself and appropriate expectations would help to encourage referral uptake.

## Conclusion

Referring patients for services even with logistic and financial help is often insufficient to encourage some patients to take up services. Table 61 summarises the predictors and barriers identified via this sub-study.

**Table 61: Summary of Barriers and Predictors of Uptake**

| Predictors of Uptake (Quantitative) | Barriers to Uptake (Qualitative) |
|---|---|
| **Sirajganj:** | **Sirajganj and Natore**[32]**:** |
| Univariable:<br>– Urban residence<br>– Paternal Literacy<br>– Low monthly Income<br>– Presence of Physical Impairment or Epilepsy<br>– Lack of hearing impairment<br>Multivariable (adjusted for age):<br>– Low monthly Income<br>– Presence of Physical Impairment or Epilepsy | – Referral given lower socioeconomic priority than daily survival<br>– Prohibitive direct and indirect costs of referral – uptake, even when services covered<br>– Confusion/misunderstanding of camp procedures<br>– Mobility limitations preventing travel<br>– Public transport not feasible<br>– Mothers unwilling/unable to travel alone to unknown locations<br>– Influence of other family and community members |
| **Natore:** | |
| Univariable:<br>– Maternal Literacy<br>– Monthly Income<br>– Presence of Epilepsy<br>– Lack of Visual Impairment<br>– Presence of multiple impairments<br>– Later onset of impairment<br>Multivariable (adjusted for age):<br>– Maternal Literacy<br>– Presence of Epilepsy<br>– Lack of visual impairment | |

Here we have explored how constructs identified in logistic regression models may act to discourage the uptake of referrals, such as low socioeconomic status, maternal illiteracy, distance to referral and miscommunication at the KIM Camps.

A combination of qualitative and quantitative research can provide a more holistic analysis than either methodology on its own, allowing for richer understanding of barriers and facilitator of referral uptake. Mixed methods research can be a useful tool to understand and overcome these barriers, and ultimately support children and families in receiving the services they need.

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[32] In Sirajganj, the pilot study, the service cost of referrals only was met by the project, except for parents in the lowest socio-economic strata deemed unable to finance this independently, in which case transport costs were included. As explained above, this protocol caused confusion and was adapted in the main study (Natore and Bogra) so that all children provided with referrals were also funded for not only the direct service costs but additionally the associated transport costs.

# Bangladesh Qualitative Report – A Summary

**The below is a summarised account. The full paper is currently unpublished but will shortly be available on http://disabilitycentre.lshtm.ac.uk/ [46].**

## Summary of "Understanding the Challenges and Barriers of Life of Children with Disabilities in Bangladesh: A Qualitative Study"

**Prof. Muhit Mohammed, Bangladesh**

## Background

Research on children with disabilities in Bangladesh has a history or focusing on the epidemiology of major impairments or conditions, risk factors, and the development , the validation of screening tools, and surveys.

Limited data exists on the reality for children in the country living with disabilities, the barriers they face, attitudes towards them and their participation in education, family life and wider society.

## Aim

To develop a comprehensive understanding of the needs, barriers, current situation and daily lives of children with disabilities and to determine the outcome of the project intervention[33].

**Photo 12: Wheelchair distribution, Bangladesh**

## Specific Objectives

- To gain insight into the realities of daily living with an impairment or disability from the children and families' perspectives
- To explore the family and community needs in wider terms in order to identify the type of interventions they feel are most important for them
- To investigate the environmental barriers for children living with impairments in Bangladesh
- To investigate the outcome of the project intervention for the children and families in order to ascertain to what extent it had an effect on their daily lives[34].

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[33] Unfortunately, due to delays in certain activities, the latter objective of investigating the impact of the project intervention for the children and their families could not be met.

[34] As above.

## Methods

The study used Focus Group Discussions (FGDs) with children with disabilities, their caregivers, community members, members of Disabled Persons' Organisations and adults with disabilities, involving a total of 103 individuals (Table 62).

Participants were selected using a theoretical sampling strategy and question sets were framed within the International Classification of Functioning (ICF) framework.

**Table 62: Qualitative Cohort**

| Participant Group | Number of FGD | Number of Individuals | | |
|---|---|---|---|---|
| | | **Male** | **Female** | **Total** |
| Children with physical impairments | 1 | 0 | 10 | 10 |
| Children with physical impairments | 1 | 10 | 0 | 10 |
| Children with epilepsy | 1 | 6 | 4 | 10 |
| Children with hearing impairments | 1 | 2 | 1 | 3 |
| Parents of children with physical impairments | 1 | 3 | 7 | 10 |
| Parents of children with epilepsy | 1 | 5 | 5 | 10 |
| Parents of children with hearing impairments | 1 | 4 | 6 | 10 |
| Community members (rural) | 1 | 7 | 3 | 10 |
| Community members (urban) | 1 | 6 | 5 | 11 |
| Disabled Persons' Organisation members | 1 | 4 | 6 | 10 |
| Adults with disabilities | 1 | 6 | 3 | 9 |
| **Total** | **11** | **53** | **50** | **103** |

Each FGD was recorded and transcribed first into the local language (Bangla) and then into English. Emerging themes were developed, indexed, charted and interpreted for the results.

**Photo 13: Boys with Physical Impairments, Bangladesh**

## Key Findings

- Lack of understanding and the negative attitudes of family members, community members, peers and school teachers can adversely affect the participation of children with disabilities in school, social occasions and relationships:

*"They [outsiders] say look how the lame walks! It is impossible to get ourselves outside. We can't go anywhere." – Physically impaired male child*

- The range of experience felt by children with disabilities is incredibly assorted, with some children actively included in household and social duties and activities, and others excluded.
- Children with different types of impairment, and different severities of impairment, face diverse misconceptions and barriers. Children with physical impairments are more likely to be misunderstood as physically dependent on others and excluded from household chores and events, and children with epilepsy face exclusion from their peers, due to the perceived uncertainty and fear of their seizures.
- Parental wariness and cautiousness can inadvertently limit a child's participation and inclusion
- Many children with disabilities and their caregivers show great resourcefulness in adapting their environments to their abilities. The success of this is often dependent on community perceptions and responses.
- Children who had received medical interventions to increase their functioning levels reported positive impact and change in their lives:

*"When he was not operated he suffered badly by the surrounding people in school. Children called him lame and cleft lipped and many more ill words. For this reason my son was reluctant to go to school. Now, after the operation, the situation has changed." – Father of physically impaired child*

## Recommendations

- Increased awareness and education about children with disabilities is needed amongst all community groups – especially caregivers and families of children with disabilities, educators and school students and religious and community leaders.
- Individual resourcefulness and adaptations should be scaled up and facilitated by healthcare providers and government policy to fulfil the potential of all children with disabilities, who remain restricted by lack of access.
- Greater environmental modifications are needed to increase inclusion in education. This includes not only assistive devices and physical access improvements, but also educators trained in alternative communication methods and positive attitude reinforcement.

# Discussion and Recomendations

## The Usability of KIM to Identify Children with Disabilities in Low Resourced Settings

In both countries, the methodology showed high sensitivity but low specificity, meaning that the KIs effectively found children with targeted impairments or epilepsy in their communities, but also brought to the camp quite large numbers of children who did not meet the study criteria. The high sensitivity in both countries means that KIM is a viable tool for case detection of those in need of rehabilitation and treatment services. The lower specificity is of concern in terms of planning for the number of children who may be seen at each camp but does not have the consequences of missing children whose prognosis may suffer if they are not picked up in time.

The study focused on the more severe grades of sensory and physical impairments, alongside Epilepsy (generalised tonic-clonic seizures) only. Despite this, children with all grades were brought to the camps, showing that a limited scope does not improve efficiency of the method. In the context of the healthcare systems in Bangladesh and Pakistan, it is unsurprising that children with other unmet healthcare needs or non-targeted impairments were brought to the KIM Camps by KIs in the hope of medical intervention, and indicative of its potential use in screening child disability and unmet healthcare needs amongst children universally.


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**Photo 14: Mother and child, KIM Camp, Bangladesh**

Very low numbers of children with the targeted moderate or worse impairments were identified amongst the normative (Non KI Listed) cohort in the Bangladesh KIM, meaning that KIs appeared to effectively identify almost all children with disabilities in their villages as per the criteria they were given. However, the numbers of children identified with bilateral moderate or severe hearing impairment in the KIM (a prevalence of 0.3 children per 1,000 confirmed via clinical screening, and 2.0 per 1,000 presumed but not tested) differed substantially from the numbers identified through household screening (6.4 per 1,000). This is partly because of the inability to confirm hearing impairment at the KIM Camps due to field testing issues described earlier in this report, but may also mean that children with more moderate hearing impairments were missed in the KIM, and will need further investigation before it can be recommended as a definitive method concerning identification of children with moderate or severe bilateral hearing impairment.

In Pakistan, no Household Survey was conducted. However, 24.8% of Non KI Listed children screen positive as per the study criteria – meaning that KIs were not effectively identifying all children meeting the study criteria in Pakistan. Potential explanations for this include the KI’s not having performed effectively (whether due to training or to difficulties in undertaking the KI role within the national political context), data being an inaccurate representation of the field work, the Non KI Listed children not having been selected randomly or the incidence of the targeted conditions in Pakistan being very high. Further investigation and testing is therefore needed before the KIM can be recommended as an effective method in Pakistan for identifying all children with the study targeted impairments and epilepsy.

- Key Informants in Bangladesh were shown to be effective at identifying almost all children with significant physical impairments, bilateral visual impairments and epilepsy in their communities
- Given the discrepancy between numbers of children identified with hearing impairments in the Household Survey and in the KIM, and the difficulties encountered in field testing for hearing impairment, further investigation is recommended to establish whether all children with moderate or worse hearing impairments are picked up by KIs in Bangladesh
- Data in Pakistan suggests that KIs missed up to 25% of children with targeted impairments or conditions in their communities, requiring further investigation into why.

## Using KIM to Estimate Prevalence and Incidence of Targeted Impairments and Health Conditions in Children

Through comparison of the study findings using the Key Informant method and the Household Survey approach, it is possible to draw observations on prevalence and incidence of specific impairments and health conditions related to child disability from the results of the KIM study in Bangladesh. The Clinical Data Form developed by the project (see Appendix 2) and completed by the multi-disciplinary medical team provides comprehensive information on the overall health condition and clinical history of each child screened. Data collected, using objectively evaluated clinical screening tools, can be used to gauge the type and severity of each child's impairment. With further investigation and clarification of underlying conditions and pathways to impairment, this information can also be used to estimate the proportion of preventable and non-preventable causes of impairment, assisting in planning for health information strategies to minimise preventable impairment and service planning to maximise rehabilitative services.

Equivalent numbers (using 95% confidence intervals) of children with bilateral visual impairment, significant physical impairment and epilepsy were identified in Bangladesh using both the KIM and the Household Survey, validating the ability of KIs to identify all children with those targeted impairments and health conditions in their communities.

In the absence of a Household Survey, results in Pakistan could not be validated. However, the large number (almost 25%) of Non KI Listed children in the Pakistan cohort screening positive for targeted impairments or epilepsy requires caution in using the data to estimate prevalence and incidence.

- Clinical Data Form used in KIM provides wealth of useful information to estimate prevalence and incidence of specific impairments and health conditions amongst children in Bangladesh based on the study findings
- Care must be taken when estimating prevalence/incidence of hearing impairment amongst children in Bangladesh due to problems listed above
- Using the Pakistan data to estimate prevalence and incidence of targeted impairments and conditions requires caution

## Using KIM to Plan and Support District Level Services

The study provides information on the aetiology of each screened child's underlying health conditions, the pathways through which these may lead to impairment and/or functioning limitation and the appropriate interventions offered in each case. This information, alongside the cost information gathered and summarised, is exceptionally useful in terms of district-level planning of services. With further in-depth investigation, estimates can be generated as to what percentage of child disability is avoidable, and how it can be avoided; and what percentage is unavoidable and how best to identify and rehabilitate from an early age so as to maximise wellbeing and participation.

The pre-emptive mapping and analysis of available and missing referral services available for all children with disabilities in KIM is a further benefit of the methodology in terms of health service planning. The exercise provides service providers across the health system with detailed information on strengths and gaps within the system as per the information collected on services needed. Though data presented is mostly in relation to primary and rehabilitative health services, the method also provided data on education enrolment rates and

**Photo 15: KI Retraining, Bangladesh**

therefore has potential to be of use in the educational sector. This would require the involvement of inclusive education specialists to map and advise on inclusive education facilities, policies and resources available to increase the participation of children with physical and sensory impairments, or epilepsy in education.

Through analysis of the costs incurred by the project in providing referral services (see page 58), it is also possible to estimate the costs of a one-time medical rehabilitative service for children in a defined population. Additionally, the mixed-method Barriers to Service Uptake element of the project (see page 79) underlines the importance of incremental costs associated with referrals for medical intervention, given the low socio-economic status of the majority of the target population. All the above information can provide support to policy makers in planning of appropriate services – specifically in terms of estimating the numbers and costs of services needed, plus barriers to take up and how to address those.

In Bangladesh, the provision of services by a combination of state and non-state actors can be better integrated using data provided on costs and numbers, and budgets can be adapted accordingly to improve efficiency in spending outcomes. Moreover, the methodology could be extended to incorporate a specific health system support mechanism that not only identifies gaps and costs but works with local systems to support their training and resource needs.

- Data collected of numbers and costs of appropriate referrals, along with referral service mapping can help in planning and management of services at the district level
- Data has potential to be used to estimate avoidable/non avoidable impairments and appropriate strategies for avoidance/rehabilitation
- Involving inclusive educational specialists and policy makers to include access to education within referral mapping and follow up procedures recommended
- Development of a health system support mechanism suggested so as to work with local systems to identify resource and training gaps and needs

## Maximising Engagement of Local Stakeholders to Embed KIM Results

A formalised Task Force team of key local stakeholders was established in Bangladesh, comprising members of local disability organisations, academics and policy makers. Due to the ongoing political instability, it was not possible to establish the same in Pakistan, although the project team nevertheless ensured to engage relevant stakeholders to the greatest extent possible.

The Dhaka Task Force in Bangladesh was formed with specific terms of reference and responsibilities (see page 25 for more information). The main aim of this was to provide the project with local insight, and to provide opportunities to facilitate the link between the project's results and relevant actors from the outset. It was anticipated that a long term link would be established both in terms of service provision for children identified with unmet medical or rehabilitative needs through the study, and in terms of the local stakeholders' use of the study findings in their own advocacy and activities.

Members of the Task Force provided invaluable input to the project's design and activities, and showed great enthusiasm on taking forward the results of the study to use in their own advocacy work. However, challenges were faced in maintaining meeting attendance from the Task Force, due to relationships between members and misunderstood expectations of funding from the project to the service providers. Future studies would benefit from signing Memorandums of Understanding with prospective Task Force members on their responsibilities and involvement with the project – specifically in terms of provision of services and follow up of the cohort.

- Creation of a Task Force made up of local stakeholders in Bangladesh provided invaluable local insight and take up of results. However, formalisation of this role to include responsibilities in terms of provision of services and long term follow up is advised

## Advocacy for Children with Disabilities

In both Bangladesh and Pakistan, great achievements in reducing infant mortality have been instigated by the Millennium Development Goals and other strategies. Priorities must however also include child morbidity and child disability, with impetus to quantify numbers and appropriate interventions to maximise child wellbeing and minimise preventable impairment.

The qualitative components of the study in particular, alongside the quantitative data on access to education and health care services amongst the cohorts, emphasise the many barriers to participation faced by children with disabilities identified in the study. Of great importance is the heterogeneity of these barriers, and the understanding that specific interventions, in isolation, are inadequate. Moreover, it has been clearly documented that the present study targeted a sub set of moderate or worse impairments or health conditions, and does not claim to represent all children with disabilities. Positive attitudes, inclusive systems and policies and access to appropriate services are interrelated and all are necessary components in ensuring optimum wellbeing for children with disabilities.

Fazal [47], in a study of the readiness of Pakistani schools to provide inclusive education, stated the following four main barriers:

- Unavailability of resources or guidelines on how to implement the Government of Pakistan's *National Plan of Action on Education for all (2001 – 2015).*
- Lack of awareness amongst teachers about how best to include children with disabilities – particularly those with learning difficulties or in need of teaching adjustments or additional time.
- Large class room sizes that limit the teachers' ability to interact individually with each child

**Photo 16: Community Dissemination Session, Bangladesh**

- Lack of physical accessibility of school environment

*(adapted from Fazal [2012])*

The above findings are echoed in the present study, which identified lack of access due to unacceptability of disability by educators, lack of appropriate environmental modifications and caregiver concern about learning opportunities.

The study's qualitative components in particular, alongside quantitative analysis of access to education, highlight the multiple barriers to participation felt by children with disabilities. This information can be used by stakeholders to advocate for their inclusion and participation.

## The Ongoing Role of Key Informants

Key Informants in Bangladesh expressed strong desire to continue providing information and assistance to members of their communities about child disability, leading to the piloting of a secondary KI training module (see page 22). Providing a secondary module led to the emergence of KI-Trainers (KITs) from amongst the original KI cohort, who went on to provide training on the second module to a selection of KIs from their locality. This builds capacity and potential for community-based mid-level workers who in future could be built into the healthcare system and provide follow up and support to replace the study's Community Mobilisers.

Qualitative research in Pakistan undertaken by Lasi et al. (2012) found the perceptions of mothers of disabled children (reported by LHWs) to be no/incomplete immunisation, inadequate care during the antenatal period, efforts to abort pregnancy using home remedies, the mothers' ill health, pre-term birth and insufficient spacing. Lady Health Workers themselves in the study perceived consanguineous marriages (where husband and wife are blood relations) as the main cause of disability, noting patterns of disability within specific families [27].

LHWs in Pakistan already provide links between communities and healthcare services, and are very knowledgeable on maternal and child health but are not taught about child disability. The introduction of further modules within their training on prevention, early intervention and management of child disability could have considerable positive impact on the lives of children with disabilities in Pakistan, using a key community resource already dominant in remote areas. This adds strength to Lasi et al. (2012) 's evidence regarding the plausibility of incorporating prevention, early identification and management of disabilities amongst Pakistani children into the role of the country's 100,000 LHWs. However the motivational levels of government functionaries to work voluntarily on a project need to be carefully assessed, given the problems encountered with identification of children with targeted impairments or epilepsy in Pakistan.

- Pilot community training module in Bangladesh well received by KIs, equipping them with the capacity to advocate for children with disabilities and to provide ongoing links between the community and health system.
- Pakistan KIs included many Lady Health Workers, who already perform a similar community-health system role and could potentially receive additional training on child disability. However, their motivation to do so must be assessed, given the findings in Pakistan.

## Transferability and Potential Use Within Community Based Rehabilitation (CBR) programs

KIM has the potential to be a valuable community-based resource. The focus on local volunteers who not only identify children with disabilities but inform caregivers on access to services and concessions and provide long-term linkages with health systems resonates strongly with aspects of the Community Based Rehabilitation model. Moreover, the KI training modules developed have proven effective in training volunteers to screen for specific impairments and health conditions, and could be formally offered to CBR worker training programs if deemed appropriate to a specific program's objectives and needs. This requires the development of a toolkit or stand alone package that could be field tested for appropriateness in different settings and if so, shared and replicated by organisations in any country wishing to undertake a KIM to identify children with targeted impairments or health conditions.

The current structure of the KIM methodology, however, is highly dependent on mid-level, paid Community Mobilisers (CM) who played an invaluable role in coordinating KI activities, KIM Camp logistics etc. To integrate the key elements of the methodology into any community based health or rehabilitation program, and therefore the wider health system, the CM coordination role must be replaced by that of a mid-level, locally-based health-worker. Without mid-level coordination, supervision and follow up, retention of KIs and continuation of long-term voluntary follow up cannot be guaranteed.

- Building a tool kit or package to allow transferability of the KI method and protocols could provide useful input to CBR or community health programs if deemed context and situation appropriate.
- Long term sustainability of the KIM method would require locally-based, mid-level community workers to replace the current "Community Mobiliser" role within the method.

# Collated Summary Discussion/ Recommendation Points

- Key Informants in Bangladesh were shown to be effective at identifying almost all children with significant physical impairments, bilateral visual impairments and epilepsy in their communities
- Given the discrepancy between numbers of children identified with hearing impairments in the Household Survey and in the KIM, and the difficulties encountered in field testing for hearing impairment, further investigation is recommended to establish whether all children with moderate or worse hearing impairments are picked up by KIs in Bangladesh,
- Data in Pakistan suggests that KIs missed up to 25% of children with targeted impairments or conditions in their communities, requiring further investigation into why.
- Clinical Data Form used in KIM provides wealth of useful information to estimate prevalence and incidence of specific impairments and health conditions amongst children in Bangladesh based on the study findings
- Care must be taken when estimating prevalence/ incidence of hearing impairment amongst children in Bangladesh due to problems listed above
- Using the Pakistan data to estimate prevalence and incidence of targeted impairments and conditions requires caution
- Data collected of numbers and costs of appropriate referrals, along with referral service mapping can help in planning and management of services at the district level
- Data has potential to be used to estimate avoidable/non avoidable impairments and appropriate strategies for avoidance/rehabilitation
- Involving inclusive educational specialists and policy makers to include access to education within referral mapping and follow up procedures recommended
- Development of a health system support mechanism suggested so as to work with local systems to identify resource and training gaps and needs
- Creation of a Task Force made up of local stakeholders in Bangladesh provided invaluable local insight and take up of results. However, formalisation of this role to include responsibilities in terms of provision of services and long term follow up is advised
- The study's qualitative components in particular, alongside quantitative analysis of access to education, highlight the multiple barriers to participation felt by children with disabilities. This information can be used by stakeholders to advocate for their inclusion and participation.
- Pilot community training module in Bangladesh well received by KIs, equipping them with the capacity to advocate for children with disabilities and to provide ongoing links between the community and health system.
- Pakistan KIs included many Lady Health Workers, who already perform a similar community-health system role and could potentially receive additional training on child disability. However, their motivation to do so must be assessed, given the findings in Pakistan.
- B Building a tool kit or package to allow transferability of the KI method and protocols could provide useful input to CBR programs if deemed context and situation appropriate.
- Long term sustainability of the KIM method would require locally-based, mid-level community workers to replace the current "Community Mobiliser" role within the method.

**Photo 17: Child with Congenital Deformity, Bangladesh**

# Limitations and Further Opportunities for the Methodology

## Security Issues in Pakistan

Security issues within Pakistan external to the project team created substantial delay and disruption to project activities and reporting. This unfortunately led to limitations in the quantity of data collected. Consequently, composite descriptive statistics only are available for Pakistan, and expanded data is unavailable, to the detriment of project outcomes.

## Impairment Based Definition of Disability

As referred to throughout this report, the study objectives necessitated a definition of child disability that was objectively identifiable by clinical examination within a field-camp setting. Consequently, the study focused on moderate and severe grades of bilateral sensory impairment (visual or hearing), significant physical impairment severely affecting the child's functioning and generalised tonic-chlonic seizures (epilepsy). To maximise programmatic usability, the methodology will need to be tested for all grades of impairment, including mild or moderate impairment and intellectual impairments. Moreover, to fully integrate the methodology within the ICF framework, disability definitions must embrace participation restrictions and lack of access to key services such as education.

## Field Conditions and Inability to Confirm Diagnoses

The study faced difficulties in confirming bilateral hearing impairment, due to large numbers of children presenting to the KIM Camps with discharging ears and other conditions that prevented confirmation of severe bilateral hearing impairment via audiometry. Given the study objectives, it is necessary to ensure that screening methods are appropriate for field conditions. This may include utilising new techniques for measuring child hearing that allow screening in the presence of discharging ears. Alternatively, additional measures can be employed to ensure that children with discharging ears are provided with prescriptions for the condition and invited to attend a secondary camp/are visited by an ENT specialist at a later date to verify results.

## Exclusion of Intellectual Impairment

The decision to exclude intellectual impairment and learning delay from the targeted child disabilities in the study resulted from both ethical considerations regarding lack of referral services, and the unavailability of validated field-tools for screening. A priority for future studies must be the effective incorporation of children with intellectual impairments and learning delay into the study design, especially considering anecdotal data on the additional stigmas often felt by children with this group of disabilities. It is imperative that data is collected where possible so as to leverage policy-makers to increase expenditure and dedication towards building appropriate services for children with disabilities.

## Follow up of Referral Interventions

Interviews undertaken with children one-year post intervention elucidated that in some cases, children identified with epilepsy and provided with a two year supply of anti-epileptic medication (with quarterly follow up by a local paediatrician) were still suffering from seizures. The in depth report on barriers to uptake elucidated some of the reasons for non-compliance (with a 1-2 days gap in medication enough to increase seizures) but close follow up is necessary to ensure appropriateness of intervention and follow up. Development and focus on a long term strategy for follow up is important, giving the evolving nature of child disability and growth. For example, follow up checks on assistive device maintenance and replacement as the child grows, or on future surgeries for children identified with cleft lip/palate or club foot, is imperative. This gives further weight to the recommendation to incorporate the strengths of the KI methodology within a CBR framework and to engage with local and established service providers.

## Community Advocacy and Local Stakeholder Engagement

The piloted KI Community Module provided a second round of training to a subset of the original Bangladesh Key Informants, based on their expressed desire to act as long term disability advocates in their communities. This module focused on community advocacy, equipping Key Informants with information on disability allowances and services and refreshing their training on child disability identification. With further implantation into the local healthcare systems, Key Informants have the capacity to provide a long-term link between service providers and community members.

## Use of Caregiver Report and Sub-set of Washington Group Questions

The Washington Group short set of six questions on key functioning domains or basic actions were developed for use in National Census screening or in surveys not primarily conducted to ascertain information on disability (e.g labour force or living standard surveys), whilst an extended set was developed for use in surveys focused on functioning [47]. The use of only five out of these six questions in the current survey must be noted. Moreover, it was developed as a self report for adult disability, and not as parental/caregiver report on child disability. The short question set was utilised in the current project as a proxy for self reported disability, given the limited time available to conduct the full questionnaire and given the limited availability of validated child self-report questions. The Washington Group is currently in the process of piloting a question set developed specifically for parental report of child functioning, and future studies would benefit from using this tool, and of other tools focusing on child self-report, once available.

## Further Planned KIM Activities Between CBM and the International Centre for Evidence in Disability

Due to the findings of this and other related studies, CBM is amongst a consortium of donors currently funding a KIM in Malawi. The project, beginning in 2013, will utilise and hone the training tools and methodologies developed in the present study, learning from and building on the experiences documented within this report.

CBM is also funding a KIM in Turkana Region, Kenya, as a method for identifying children with disabilities to ascertain whether or not they have equal access to nutritional programs run by the Kenyan Red Cross.

# 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[ab].

## 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**

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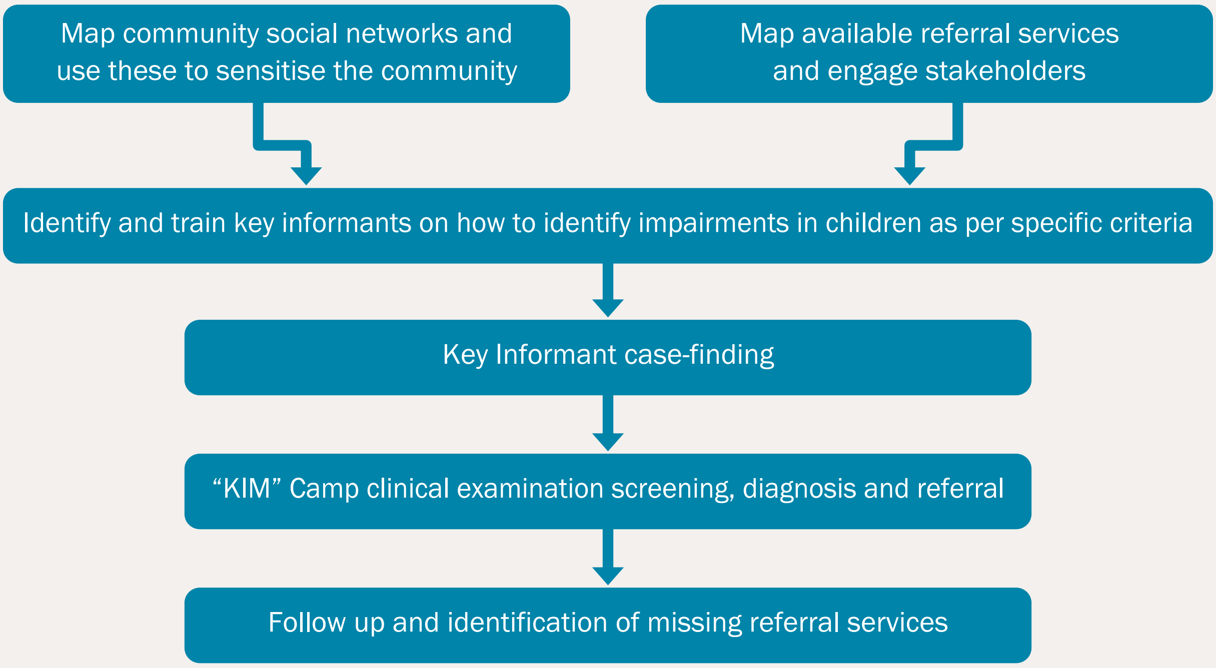
[a] The United Nations Convention of the Rights of Persons with Disabilities and Optional Protocol (2008) is available at www.un.org/disabilities

[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**



## 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)

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[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 | 6,056 |
| Total Cost per Child Covered | £0.57 | £5.76 |
| Total Cost per Child Diagnosed | £63.12 | £431.02 |
| Total Cost per Child Referred | £108.24 | £1,306.12 |
| ***Excluding Treatment and Travel Costs for Children*** | | |
| Total Cost per Child Covered | £0.37 | £4.84 |
| Total Cost per Child Diagnosed | £40.97 | £362.06 |
| Total Cost per Child Referred | £70.26 | £1,097.15 |
| **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.

# Abstracts and Summaries

Bedford J., Mackey S., Parvin A., Muhit M. and Murthy GVS. *Reasons for non-uptake of referral: children with disabilities identified through the Key Informant Method in Bangladesh*, Special Edition of the Journal of Disability and Rehabilitation In Press

**Purpose:** To identify reasons for the non-uptake of referral for children with disability identified though the Key Informant Method in Bangladesh.

**Method:** Core data was collected and analysed using qualitative methodologies. 51 semi-structured interviews were completed with parent (s) of a children who had attended a screening camp at the invitation of a Key Informant, but had not taken up their subsequent referral for health or rehabilitative services. Thematic analysis of the interview data resulted in emerging trends that were critically analysed according to the research objective.

**Results:** Seven thematic reasons for non-uptake of referral were identified: severity of the disability; family and community; direct and associated cost; location of referral; negative camp experience; deliberate non-uptake; and procedural problems. Parents often discussed multiple reasons for non-uptake, interrelating socio-cultural, logistical and experiential factors.

**Conclusion:** Understanding the reasons parents of children with disability do not take up referral is important for the design and implementation of appropriate, relevant and contextual medical and rehabilitative services. The role of Key Informants may be developed from case detection, to include facilitation of effective and efficient uptake of services.

Nesbitt RC., Mackey S., Kuper H., Muhit M. and Murthy GVS. *Predictors of referral uptake in children with disabilities in Bangladesh: exploring barriers as a first step to improving referral provision*, Journal of Disability and Rehabilitation 2012;34 (13): 1089-95. Epub 2011 Dec 3. (2011). Online doi: 10.3109/09638288.2011.634943.

**Purpose:** Making services available to children with disabilities in low- and middle-income countries does not guarantee their use. This study aims to identify factors associated with the uptake of referrals in order to investigate barriers to service use.

**Methods:** Children with impairments identified in two districts of Bangladesh were invited to attend screening camps where their condition was confirmed; they were provided with referrals for rehabilitation and treatment services. Predictors of referral uptake were identified using logistic regression.

**Results:** Overall referral uptake was 47%, 32% in Sirajganj and 61% in Natore. There was no association between age or gender and referral uptake. Factors predictive of referral uptake were higher income in Sirajganj (OR=2.6 95%CI 1.4-5.0), and the districts combined (OR=1.6 95%CI 1.1-2.1); maternal literacy in Natore (OR=1.6 95%CI 1.0-2.5); and epilepsy in all three models (Sirajganj: OR=2.6 95%CI 1.7-4.0; Natore: OR=13.5 95%CI 6.5-28.3; Combined: OR=4.6 95%CI 3.3-6.5). Physical impairment was associated with increased odds of uptake in Sirajganj and in the combined model (OR=2.7 95%CI 1.8-4.1; OR=3.34 95%CI 2.2-5.2).

**Conclusion:** Even when some logistical and financial assistance is available, children with impairment from low-income families may require additional support to take up referrals. There may be greater willingness to accept treatment that is locally provided, such as medication for epilepsy or therapy at village level.

# Appendix 1: Information Sheet (Bangladesh) for Parents and Guardians of Children Participating in the Study

## Background

You and your child are being invited to take part in the Childhood Disability Study in Bangladesh.

Before you decide whether to take part or not we want to make sure that you understand why the study is being done and what it will involve. There may be words in this information sheet that are unfamiliar to you. Please ask us to explain anything you do not understand, and take your time deciding whether you would like to take part in the study.

The Child Sight Foundation (CSF) has been working with the International Centre for Eye Health, London School of Hygiene and Tropical Medicine, London UK and the Sightsavers International for the past five years to find out why children become blind. As a direct result of this project a large number of blind children were given treatment or had surgery so that they could see again. This meant they could go back to school and play with other children. Now the Child Sight Foundation will help to find children with other disabilities so that they too get the treatment they need.

## What is the Purpose of the Study?

Some children suffer from problems with their hearing, or they cannot use their arms or legs properly, or they have fits. We don't know how many children have these problems in Bangladesh. The study will help us to find children who have these conditions and make sure they get the treatment they need. Information from the project will also be used to estimate how many children in Bangladesh have each of these disabilities so that services can be planned for them.

## What do we Have to Do?

If you have been invited to participate in the study it is because there is a child aged 0-15 years in your house who may have a problem which prevents them from doing some or all the things other children of the same age do. The first thing we will do is examine your child to see whether they have a problem or not, and whether they could benefit from treatment. If your child does have a problem which could be helped by treatment we will advise you where to take your child.

We will also talk to you to find out what treatment your child has had already, and if the child has not had any treatment we would like to know why this is the case.

After your child has had the necessary treatment we will visit again after one year to see if the treatment has changed what he or she can or cannot do and in their schooling.

## Do I Have to Agree to Take Part?

You/your child do not have to take part in this study if you don't want to. You are free to decide. If you do agree for you/your child to take part, you will be asked to sign or put your thumb print to show that you have understood this information and that you agree for you/your child to take part in the study. If you agree for you/your child to take part in the study but you do not want to give your signature or thumb print, we will ask an independent person to come and sign that they have witnessed you giving agreement. We will give you a copy of the form. If you choose that you/your child should not take part, you do not have to give any reason and your child's care will not change in any way.

## How Many Times Will I/My Child Have to Participate?

We will talk to you and your child once at home. This will take 10-15 minutes. If your child has a problem he or she will be examined by a doctor who will come to your community a few days later to examine all children at a central location in the community. This will take about 30 minutes. Some children may need to go to the hospital for treatment. We will visit the children who have been treated again after one year to ask some further questions. This will take 15 minutes.

## Are There any Risks in Taking Part?

There is no risk of physical harm to your child due to the tests that the doctor will do in the village. The tests that the doctor does will depend on the problem that your child has. If your child has a problem with their hearing, their ability to hear will be tested and their ears will be examined. If your child has problems with their arms and/or legs, then these will be examined. If your child has fits the doctor will talk to you so you can describe what happens, and the doctor will examine your child.

## What Will be the Benefits to the Children?

Most children will not need any further treatment. Children who need treatment in the community will be given the treatment without you having to pay for it. If they need to visit a hospital or another place for services, we will help you to reach the hospital without any cost. At the hospital, the examination will be free but you may have to pay a small amount for some services. We will come back and see how your child is doing after one year and if anything else needs to be done then we will help you again.

## Can I Withdraw Myself or My Child From the Study?

Even if you agree for you/your child to take part, you can change your mind at any time, without giving a reason. If you decide that you/your child should stop taking part at any point in the study, your child's care will not change in any way.

## Confidentiality: Will My Participation in this Project be Kept Confidential?

All the information provided by you and your child will be kept completely secret. This means that your family names or children's names will not be written on any of the forms and only special numbers which will be given to each child will be used.

## Financial Arrangements

We will not give you/your child any extra money to take part. However we will pay for you and your child's visit to the hospital the first time if it is required. We will not be able to pay for future visits for treatment if the child needs to be taken back to the hospital after the study is completed.

## Who has Approved this Study?

This study has been reviewed and approved by the Bangladesh Medical Research Council and the London School of Hygiene and Tropical Medicine, London to make sure that study participants are protected from harm.

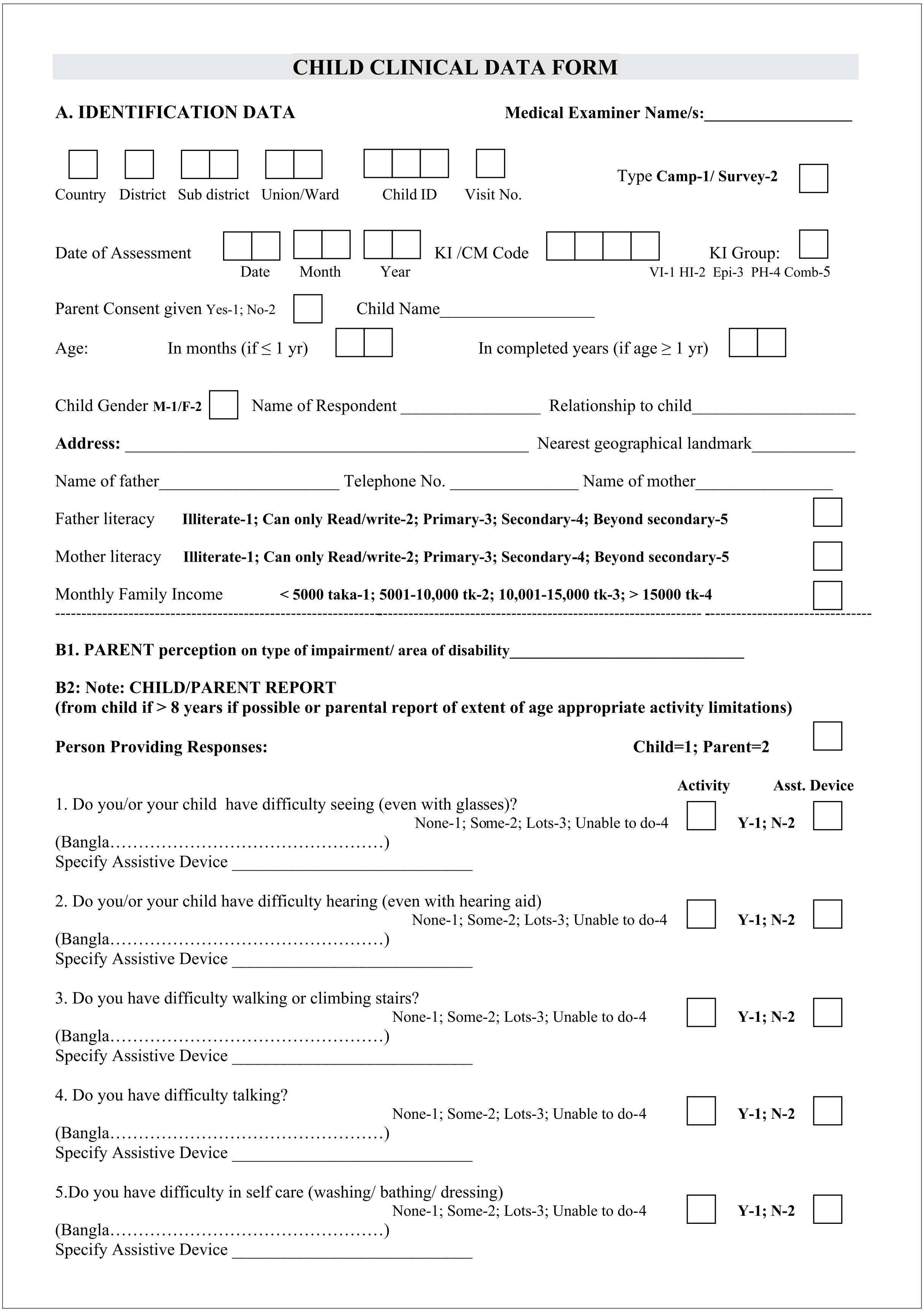
## If You Have Any Questions

If you have any questions, please contact Mr/Ms XXXX either now or at any time in the future. The postal address and telephone numbers of the Project team are given at the top of this information sheet. The telephone number of Mr/Ms XXX is XXXXXX

## Action

Please read this information sheet carefully and also make sure that you understand what it is saying. If you are not able to read it yourself, ask a member of the study team to read it out to you. Please keep this information sheet with you. If you are unsure of anything that it contains, please ask one of the staff members of the study team today or at any other time. If you give your support and are happy to participate in the study, you will be asked to sign a form, in the presence of a witness from your own community.

# Appendix 2: Child Clinical Data Form



## CHILD CLINICAL DATA FORM

**A. IDENTIFICATION DATA** **Medical Examiner Name/s:**_________________

| | | | | | | |
|---|---|---|---|---|---|---|
| ☐ | ☐ | ☐☐ | ☐☐ | ☐☐☐ | ☐ | Type **Camp-1/ Survey-2** ☐ |
| Country | District | Sub district | Union/Ward | Child ID | Visit No. | |

Date of Assessment ☐☐ Date ☐☐ Month ☐☐ Year KI /CM Code ☐☐☐☐ KI Group: ☐ VI-1 HI-2 Epi-3 PH-4 Comb-5

Parent Consent given Yes-1; No-2 ☐ Child Name__________________

Age: In months (if ≤ 1 yr) ☐☐ In completed years (if age ≥ 1 yr) ☐☐

Child Gender **M-1/F-2** ☐ Name of Respondent ________________ Relationship to child__________________

**Address:** _______________________________________________ Nearest geographical landmark____________

Name of father_____________________ Telephone No. _______________ Name of mother________________

Father literacy **Illiterate-1; Can only Read/write-2; Primary-3; Secondary-4; Beyond secondary-5** ☐

Mother literacy **Illiterate-1; Can only Read/write-2; Primary-3; Secondary-4; Beyond secondary-5** ☐

Monthly Family Income **< 5000 taka-1; 5001-10,000 tk-2; 10,001-15,000 tk-3; > 15000 tk-4** ☐

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**B1. PARENT perception on type of impairment/ area of disability**____________________________

**B2: Note: CHILD/PARENT REPORT**
**(from child if > 8 years if possible or parental report of extent of age appropriate activity limitations)**

**Person Providing Responses:** **Child=1; Parent=2** ☐

| | | **Activity** | | **Asst. Device** |
|---|---|---|---|---|
| 1. Do you/or your child have difficulty seeing (even with glasses)?<br>(Bangla…………………………………………)<br>Specify Assistive Device _____________________________ | None-1; Some-2; Lots-3; Unable to do-4 | ☐ | **Y-1; N-2** | ☐ |
| 2. Do you/or your child have difficulty hearing (even with hearing aid)<br>(Bangla…………………………………………)<br>Specify Assistive Device _____________________________ | None-1; Some-2; Lots-3; Unable to do-4 | ☐ | **Y-1; N-2** | ☐ |
| 3. Do you have difficulty walking or climbing stairs?<br>(Bangla…………………………………………)<br>Specify Assistive Device _____________________________ | None-1; Some-2; Lots-3; Unable to do-4 | ☐ | **Y-1; N-2** | ☐ |
| 4. Do you have difficulty talking?<br>(Bangla…………………………………………)<br>Specify Assistive Device _____________________________ | None-1; Some-2; Lots-3; Unable to do-4 | ☐ | **Y-1; N-2** | ☐ |
| 5.Do you have difficulty in self care (washing/ bathing/ dressing)<br>(Bangla…………………………………………)<br>Specify Assistive Device _____________________________ | None-1; Some-2; Lots-3; Unable to do-4 | ☐ | **Y-1; N-2** | ☐ |

**[Note: For any 'non applicable' questions – write 0 throughout form]**

## C. EDUCATIONAL STATUS OF CHILD

1. Is the child currently attending **mainstream** school? (If No-go toC3) **Yes-1; No-2** ☐

2. Type of school child is attending: **Primary-1; Madrassa-2; Secondary-3** ☐
(Go to section D )

3. Is the child currently attending any special school? **Yes-1; No-2** ☐

4. If not attending any school (6+yrs) – reasons why? **Working-1; School too far-2; Disability not accepted by school-3; Lack money-4; Parents refused-5; Other reason-6** (up to 2 choices) ☐☐

5. If others, please specify__________________

-----------------------------------------------------------------------------------------------------------------------------------------

## D. REHABILITATION SUPPORT FOR CHILD

1. Has the child ever received any rehabilitation services or other related support? (see list in D2) **Yes-1; No-2** ☐
**(If NO go to D4)**

2. What type of support was received? **Assistive Devices-1; Surgery-2; Therapy Exercises-3; Advice-4 Other -5** (up to 3 choices) ☐☐☐
If other, specify_______________________________________________

3. What was the type of location for accessing these rehabilitation services? (up to 3 choices) ☐☐☐
**(Go to E)** **Home based -1; NGO Centre-2; Hospital-3; Private clinic-4**

4.Reasons why child has NEVER received rehabilitation: **Not aware-1; No money-2; Transport problems-3; Others-4** ☐☐

5. If Others, Specify _____________________________________

-----------------------------------------------------------------------------------------------------------------------------------------

## E. CLINICAL HISTORY

1. Age at **ONSET**? At birth **Yes-1; No-2** ☐ Age onset in months (≤ 1 yr) ☐☐ Age onset in yrs (if age ≥ 1 yr) ☐☐

2. Was there any significant disease during pregnancy? **Yes-1; No-2** ☐

3. If problem occurred before 1 month of age: **Intrauterine-1; Perinatal (≤ 7 days)-2; Post natal (> 7 to 28 days)-3; Unknown-4** ☐

4. What was the apparent cause? **Trauma-1; Illness-2; Delayed crying-3 Unknown-4** ☐

5. Did the mother take any strong medicines/ drugs when she was pregnant with this child? **Yes-1; No-2** ☐

6. Do the parents or other relatives have the same problem? **Yes-1; No-2** ☐

7. Are the parents consanguineous? **Yes-1; No-2** ☐

-----------------------------------------------------------------------------------------------------------------------------------------

## F. GENERAL EXAMINATION

Any abnormalities noted with:

1. Face: Specify abnormality if any__________________________ **Yes-1; No-2; Not able to examine-3;** ☐

2. Mouth: Specify abnormality if any__________________________ **Yes-1; No-2; Not able to examine-3;** ☐

3. Palate: Specify abnormality if any__________________________ **Yes-1; No-2; Not able to examine-3;** ☐

4. Upper limbs: Specify abnormality if any_____________________ **Yes-1; No-2; Not able to examine-3;** ☐

5. Lower limbs: Specify abnormality if any_____________________ **Yes-1; No-2; Not able to examine-3;** ☐

6. Spine: Specify abnormality if any______________________ **Yes-1; No-2; Not able to examine-3;** ☐

7. Any other: Specify abnormality if any__________________ **Yes-1; No-2; Not able to examine-3;** ☐

-----------------------------------------------------------------------------------------------------------------------------------------

## G. PHYSICAL IMPAIRMENT

1. Compared with other children did child have delay in sitting/ standing/ walking? **Yes-1; No-2; Not Known-3** ☐

2. Does child have weakness/ stiffness/floppiness in arms or legs? **Yes-1; No-2; Not Known-3** ☐

3. Has walking/running/ climbing stairs/getting up from squatting position become <u>more difficult</u> with time for the child now or does the child have frequent falls? **Yes-1; No-2; Not Known-3** ☐

4. Does the child find it difficult (L or R) to pick up or manipulate small objects? **Yes-1; No-2; Not Known-3** ☐

---

## G5. LIST OF CONDITIONS (Please Code <u>Each</u> Box)

a. Cerebral palsy **Yes-1; No-2; Not able to examine-3** ☐

b. If Cerebral palsy present, record number of limbs affected **(1 limb-1; 2 limbs-2; 3 limbs-3; 4 limbs-4)** ☐

c. Spina bifida **Yes-1; No-2; Not able to examine-3** ☐

d. Hydrocephalus **Yes-1; No-2; Not able to examine-3** ☐

e. Polio **Yes-1; No-2; Not able to examine-3** ☐

f. Muscular Dystrophy/ Atrophy type **Yes-1; No-2; Not able to examine-3** ☐

g. Spinal Cord Injury **Yes-1; No-2; Not able to examine-3** ☐

h. Amputee (upper or lower limb) **Yes-1; No-2; Not able to examine-3** ☐

i. Club foot **Yes-1; No-2; Not able to examine-3** ☐

j. Cleft lip/ palate **Yes-1; No-2; Not able to examine-3** ☐

k. Other type of congenital deformity **Yes-1; No-2; Not able to examine-3** ☐

l. Trauma/ Burn **Yes-1; No-2; Not able to examine-3** ☐

m. Genetic disease **Yes-1; No-2; Not able to examine-3** ☐

n. Rickets **Yes-1; No-2; Not able to examine-3** ☐

o. Others **Yes-1; No-2; Not able to examine-3** ☐

p. If Others (Specify) ________________________

**G6. Is there a significant** (affecting function) **physical impairment present** (Dr) Yes-1; No-2 ☐

---

## H. EPILEPSY

1. Does your child ever have/had fits/ become rigid or lose consciousness? **Yes-1; No-2** ☐

2. Did you child ever have spasm/jerky movements of arms/legs/ whole body? **Yes-1; No-2** ☐

3. Was there any frothing at the mouth during episode? **Yes-1; No-2** ☐

4. Has your child ever suddenly fallen over or bitten tongue? **Yes-1; No-2** ☐

5. How many episodes in the last 3 months? **(enter number times)** ☐☐

6. *Has the child been seen by a medical person for this problem?* **Yes-1; No-2** ☐

7. *Does the child have medication for this problem?* **Yes-1; No-2** ☐

**8. Is there any presence of epilepsy in the child** (Dr response) **Yes-1; No-2** ☐

---

## I. VISUAL IMPAIRMENT

1. Do the child's eyes look abnormal in any way to you? **Yes-1; No-2; Not able to examine-3** ☐

2. Do you think your child has a serious problem in seeing? **Yes-1; No-2; Not able to examine-3** ☐

3. ONLY if child is aged 0-5 years:
Can the child look at and follow a moving object? **Yes-1; No-2; Not able to examine-3** ☐

4. ONLY if child is 6-18 years:
Can the child count fingers from 6 metres with both eyes open? **Yes-1; No-2; Not able to examine-3** ☐

5. **Any disabling visual impairment present?** (Dr) **Yes-1; No-2; Not able to examine-3** ☐
(presenting vision < 6/60 in the better eye)

**Visual Acuity**:
6. Method of assessing visual acuity? **Snellen's E-chart-1; Cardiff / Other card-2; Other methods-3** ☐

7. If other methods, specify ____________________________________________

|  | **Presenting** | **Pinhole** |
|---|---|---|
| **8. Visual Acuity**<br>Cannot see 6/60 in better eye-1; Cannot see 3/60 in better eye-2; Can Only see light in better eye-3; Cannot see light in both eyes-4; Cannot test but believed blind-5; Fix & Follow light (0-5 yrs) - 6 | ☐ | ☐ |

**9. Cause of Blindness/ Severe VI:** ☐☐
Whole eye (microphthalmos/anophthalmos)-1;Lens (unoperated cataract in one or both eyes)-2;
Glaucoma/ buphthalmos-3; Uvea (e.g. aniridia, uveitis)-4; Suspected uncorrected refractive error-5; corneal opacity-6;
Lens (aphakic or pseudophakic in both eyes)-7; Retina (dystrophy/detachment)-8; Optic Nerve(atrophy/hypoplasia)-9
Others -10;
If Others (Specify) ______________________________________________

---

## J. HEARING IMPAIRMENT

### Speech & Language

1. If child is > 6 months, does the child have speech or vocalization? **Yes-1; No-2** ☐
(If NO go to Hearing section )

2. Is the child's speech in any way different from other children of same age? **Yes-1; No-2** ☐

3. If the child is 2 years old: Can they say the names of familiar objects? **Yes-1; No-2** ☐

4. If the child is >=3 years old: Can the child speak whole sentences like other children? **Yes-1; No-2** ☐

### Hearing

**0-2 years**
5. Does the child react to loud noises? **Yes-1; No-2** ☐

6. If you speak normally to your child, does the child turn to look at you? **Yes-1; No-2** ☐

**Above 2 years**
7. Do you have to raise your voice to get your child's attention? **Yes-1; No-2** ☐

8. Do you have to increase the volume of the TV or radio a lot? **Yes-1; No-2** ☐

**9. Is there any disabling hearing impairment (bilateral) present** (Dr response) **Yes-1; No-2** ☐

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## K. BASIC EAR ASSESSMENT & AUDIOMETRY

| **Basic Ear Assessment** | | **Right** | **Left** |
|---|---|---|---|
| **1. Ear Pain** | Yes-1; No-2 | ☐ | ☐ |
| **2. External Ear Canal** | | | |
| - Inflammation | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| - Wax | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| - Foreign Body removal | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| - Ottorhoea (discharge) | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| - Discharge removed | Yes-1; No-2 | ☐ | ☐ |
| **3. Ear Drum** | | | |
| - Perforation | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| - Retraction | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| - Red & Bulging | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| **4. Middle Ear** | | | |
| - Ottorhoea | Yes-1; No-2; Not able to examine-3 | ☐ | ☐ |
| **5. Other cause**: Specify Right_______________ | Left________________________ | ☐ | ☐ |

**AUDIOMETRY:** To be tested at camp Yes – 1; No - 2 ☐
(Field audio for children aged ≥ 4 years (for < 4 years use OAE)

**6. Ambient Noise level** (Should NOT EXCEED 40 dBA) ☐☐

**7. Hearing Thresholds**
(enter results or code No response - 1 Not able to examine-2

| **Right** | | **Left** |
|---|---|---|
| ☐☐ | 1 KHz | ☐☐ |
| ☐☐ | 2 KHz | ☐☐ |
| ☐☐ | 3 KHz | ☐☐ |
| ☐☐ | 4 KHz | ☐☐ |

---

## L. CLINICAL DIAGNOSIS FOR CHILD:___________________________________________

1. Specify Right___________________________ ☐ Left_______________________________ ☐

2. Does parental report of impairment match medical assessment? Yes-1; No-2 ☐
**(refer to Q:B1 on 1st page)**

3. Additional Comments: ________________________________________________________________

---

## M. REFERRAL DATA

**Action Needed** **Yes-1; No-2** ☐

**Action:**

1. Advice & CBR/therapy follow up_______________________________ **Yes-1; No-2; Not applicable-3** ☐

2. Medication given/prescribed ___________________________ **Yes-1; No-2; Not applicable-3** ☐

3. Further investigations needed (Specify)___________________________ **Yes-1; No-2; Not applicable-3** ☐

4. Surgery recommended (Specify)________________________________ **Yes-1; No-2; Not applicable-3** ☐

5. Assistive device advised (Specify Type)__________________________ **Yes-1; No-2; Not applicable-3** ☐

6. Education (Specify type recommended) __________________________ **Yes-1; No-2; Not applicable-3** ☐

7. Vocational training (If above 12 years) ____________________________ **Yes-1; No-2; Not applicable-3** ☐

8. Disability Support Group advised _____________________________ **Yes-1; No-2; Not applicable-3** ☐

……………………………………………………………………………………………………..

9. To be seen by KIM Counsellor or physiotherapist Counsellor-1 Physio-2 Neither-3 ☐ ☐

10. Comments if child seen by KIM Counsellor or Physio………………………

* Please write main advice/ treatment given and briefly: **Note action for any follow up:**

- 
- 
- 
- 
-

_______________________________________________________________________________

**PedsQL** questionnaire to be administered Yes-1; No-2 ☐

(*To be completed only for those children 5+ years with diagnosis of VI/ HI/ PH impairments or Epilepsy)

_______________________________________________________________________________

**COMPLETED EXAM CODE**: (To be filled by Data Entry Officer ) **K=1 C=2** ☐

# Appendix 3: List of Figures and Tables

## List of Figures

## List of Tables

## List of Photos

## List of Maps

# References

1. The United Nations. *Convention of the Rights of Persons with Disabilities and Optional Protocol*. 2008 [cited 2012 01.05.12].
2. World Health Organization, *World Report on Disability/World Health Organization [and] The World Bank*, ed. B. World. 2011, Geneva: World Health Organization.
3. Muhit, M.A., et al., *The Key Informant Method: A Novel Means of Ascertaining Blind Children in Bangladesh.* British journal of ophthalmology, 2007. **91**(8): p. 995.
4. Kalua, K., et al., *Causes of blindness among children identified through village key informants in Malawi.* Can J Ophthalmol, 2008. **43**(4): p. 425-7.
5. Razavi, H., et al., *Prevalence and Causes of Severe Visual Impairment and Blindness Among Children in the Lorestan Province of Iran, Using the Key Informant Method.* Ophthalmic Epidemiology, 2010. **17**(2): p. 95-102.
6. Pal, D.K., T. Das, and S. Sengupta, *Comparison of key informant and survey methods for ascertainment of childhood epilepsy in West Bengal, India.* International journal of epidemiology, 1998. **27**(4): p. 672.
7. The United Nations Children's Fund (UNICEF), *Excluded and Invisible*, P. Moccia, Editor. 2006, UNICEF.
8. NATALE, J.E., et al., *Prevalence of Childhood Disability in a Southern Indian City: Independent Effect of Small Differences in Social Status.* International journal of epidemiology, 1992. **21**(2): p. 367-372.
9. Al-Ansari, A., *Prevalence estimates of physical disability in Bahrain – a Household Survey.* Disability and Rehabilitation, 1989. **11**(1): p. 21-24.
10. Maulik, P.K. and G.L. Darmstadt, *Childhood disability in low-and middle-income countries: overview of screening, prevention, services, legislation, and epidemiology.* Pediatrics, 2007. **120**(Supplement 1): p. S1.
11. Braithwaite, J. and D. Mont, *Disability and poverty: a survey of World Bank Poverty Assessments and implications.* European Journal of Disability Research, 2009. **3**: p. 219-232.
12. Filmer, D., *Disability, poverty, and schooling in developing countries: results from 14 Household Surveys.* The World Bank Economic Review, 2008. **22**(1): p. 141.
13. Peters, D.H., et al., *Poverty and Access to Health Care in Developing Countries.* Annals of the New York Academy of Sciences, 2008. **1136**(1): p. 161-171.
14. Statistics Division, B.B.o.S., *2011 Population and Housing Census: Preliminary Results*. July 2011.
15. United Nations Development Program, *Human Development Report 2010: The Real Wealth of Nations: Pathways to Human Development*. 2010.
16. United Nations Development Program, *Human Development Report 2011: Sustainability and Equity: A Better Future for All.* 2011.
17. Alam, K.J., N. Bari, and M.A. Khan, *Community Based Rehabilitation Practices and Alleviation of Poverty of People with Disabilities in Bangladesh*, in *Bangladesh Country Paper [Serial online]*. 2005.
18. The Danish Bilharziasis Laboratory for the World Bank, *Disability in Bangladesh: A situational Analysis*. 2004.
19. Titumir, R.A.M. and J. Hossain, *Disability in Bangladesh: Prevalence, Knowledge, Attitudes and Practices*. February, 2005.
20. Blanchet, K. and P. James, *How To do (or not to do)... a social network analysis in health systems research.* Health Policy and Planning, 2011.
21. Population Census Organization, G.o.P., **Pakistan Census Data 1998**. 1998.
22. Singal, N., F. Bhatti, and R. Malik, *Counting the invisible: understanding the lives of people with disabilities in Pakistan.* Research Consortium on Educational Outcomes and Poverty, 2009. **RECOUP Working Paper No. 23**.
23. Idrees, B. and R. Ilyas, *Discrimination and stigmatization of physically disabled students in a general educational environment in Pakistan: a case study.* Academic Research International, 2012. **2**(2).

24. Maloni, P.K., et al., *Perceptions of disability among mothers of children with disability in Bangladesh: Implications for rehabilitation service delivery.* Disability and Rehabilitation, 2010. **32**(10): p. 845-854.
25. Japan International Cooperation Agency Planning and Evaluation Department, *Country Profile on Disability: Islamic Republic of Pakistan*. 2002.
26. Lynd, D., *The Education System in Pakistan: Assessment of the National Education Census*. 2007: UNESCO.
27. Lasi, S.Z., A. Qayyum, and G. Rafique, *Lady Health Workers (LHWs) as Flag Bearers for Children with Disabilities in Pakistan*. 2012. Vol. 23. 2012.
28. Asadullah, M.N. and N. Chaudhury, *Religious Schools, Social Values, and Economic Attitudes: Evidence from Bangladesh.* World Development, 2010. **38**(2): p. 205-217.
29. Ahmad, M., *Madrassa Education in Pakistan and Bangladesh*, in *Religious Radicalism and Security in South Asia*, S. Limaye, R. Wirsing, and M. Malik, Editors. 2004, Asia-Pacific Center for Security Studies: Honolulu.
30. *Bangladesh Persons with Disability Welfare act (functional English Version)*, N.F.o.O.w.w.t. Disabled, Editor. 2001.
31. *State of the Rights of Persons with Disabilities in Bangladesh, 2010*. 2010.
32. Social Development Division, *Disability at a Glance 2010: A profile of 36 Countries and Areas in Asia and the Pacific*. 2010, UNESCAP.
33. World Health Organization. *International classification of functioning, disability and health*. 2001 28th September 2011]; Available from: www.who.int/classification/icf/en.
34. Muhit, M.A., et al., *Causes of Severe Visual Impairment and Blindness in Bangladesh: A Study of 1935 children.* British journal of ophthalmology, 2007. **91**(8): p. 1000.
35. WHO, *Report of the Informal Working Group on Prevention of Deafness and Hearing Impairment Programme Planning* 1991: Geneva.
36. Varni, J.W., Burwinkle, T.M., Seid, M., and Skarr, D., *The PedsQL™ 4.0 as a pediatric population health measure: Feasibility, reliability, and validity.* Ambulatory Pediatrics, 2003. **3**: p. 329-341.
37. UNICEF, *Bangladesh Country Brief*. 2005.
38. Reddihough, D.S., Collins, K.J., *The epidemiology and causes of cerebral palsy.* Australian Journal of Physiotheraphy, 2003. **49**: p. 7-12.
39. Olusanya, B.O., L.M. Luxon, and S.L. Wirz, *Maternal views on infant hearing loss in a developing country.* International Journal of Pediatric Otorhinolaryngology, 2006. **70**(4): p. 619-623.
40. Moeller, M.P., *Early Intervention and Language Development in Children Who Are Deaf and Hard of Hearing.* Pediatrics, 2000. **106**(3): p. e43.
41. Zakzouk, S., *Cosanguinity and hearing impairment in developing countries: a custom to be discouraged.* The Journal of Laryngology & Otology, 2002. **116**: p. 811-816.
42. Banu, S.H., et al., *Profile of childhood epilepsy in Bangladesh.* Developmental Medicine & Child Neurology, 2003. **45**(7): p. 477-482.
43. Pradhan, S., Ramakant, Y., *Seizures and epilepsy in central nervous system infections.* Neurology Asia, 2004. **9**(Supplement 1): p. 4-9.
44. Strand, S. and G. Lindsay, *Evidence of Ethnic Disproportionality in Special Education in an English Population.* The Journal of Special Education, 2009. **43**(3): p. 174-190.
45. Muhit M., P.P., Jewel J., Wadud S. and Lee E., *Understanding the challenges and barriers of life of children with disabilities in Bangladesh: A Qualitative Study*. 2012, Child Sight Foundation: Dhaka, Bangladesh.
46. Fazal, R., *Readiness for Inclusion in Pakistani Schools: Perceptions of School Administrators.* International Journal of Social Science and Education, 2012. **2**(4): p. 2223-2227.
47. Washington Group on Disability Statistics, *Understanding and interpreting disability as measured using the WG short set of questions*. 2009: Hyattsville.

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