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The Telengana Disability Study, India

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Cover photo caption: Participants with and without visual impairments wait for screening

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For full and summary country reports for India and Cameroon respectively, and for further resources related to this study, visit http://disabilitycentre.lshtm.ac.uk

Accessible versions of all tables/figures are available upon request

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Background

Few robust quantitative data on the magnitude and impact of disability on people's lives are available globally. Even amongst the limited evidence base that exists, different methodologies used in defining disability make comparison between countries and over time extremely difficult. These data are urgently needed to estimate the prevalence and impact of disability on people's lives, so as to plan appropriate, disability inclusive programmes, policies and societies.

Photo: A village participant reports on whether she has activity limitations

Aims and objectives

Aim:

To develop and test a best-practice population-based survey methodology to estimate the prevalence of disability in children and adults in India, and to compare the extent to which people with and without disabilities access key mainstream services and opportunities including health, education and livelihoods in Telangana State, India[1].

Objectives:

1. Develop a population-based survey methodology that can assess prevalence of i)Visual, hearing, musculoskeletal impairment and depression; and ii)Self-reported Disability

2. In Telengana State, India:

i) To estimate the prevalence of disability (impairments and activity limitations)
ii) To explore the extent to which people with disabilities (PWD) access mainstream health, education, employment and livelihood opportunities in comparison to non-disabled peers, and their experiences of participation
iii) To identify factors that predict access to health, education, employment and livelihood amongst persons with disabilities
iv) To identify barriers and facilitators which mediate access to services

Methods:

1. All-age population-based survey of disability in Mahbubnagar District, Telengana State, measuring:

   a. Self-reported activity limitations

[1] This project began in January 2014, prior to the bifurcation of Andhra Pradesh into Telengana and Andhra Pradesh. Field work took place in what is now Telengana State.

b. Clinical screening for visual impairment, hearing impairment, musculoskeletal impairment, epilepsy and clinical depression (18+ only)

2.Nested case-control study of people with and without disabilities, assessing:

a. Impact of disability on access to health, education, livelihoods, participation etc.

b. Availability of rehabilitation, inclusive education and assistive devices

Table 1: Overall Prevalence of Disability

	Total		0-17 years*		18-49 years		50+ years		Male		Female	
	n	**% (95% CI)**	**n**	**% (95% CI)**	**n**	**% (95% CI)**	**n**	**% (95% CI)**	**n**	**% (95% CI)**	**n**	**% (95% CI)**
Any disability*	**437**	**12.2 (10.6-14.1)**	**44**	**3.6 (2.6-4.9)**	**137**	**8.1 (6.0-11.0)**	**256**	**38.3 (33.6-43.3)**	**199**	**11.7 (9.7-14.0)**	**238**	**12.2 (10.9-14.8)**
Self Reported Limitations	258	7.5 (5.9-9.4)	25	2.3 (1.4-3.7)	79	4.7 (2.8-7.7)	154	23.1 (19.5-27.1)	107	6.5 (4.7-8.8)	151	8.4 (6.6-10.6)
Any moderate or severe impairment or health condition	376	10.5 (9.4-11.7)	36	2.9 (2.1-4.0)	106	6.3 (5.1-7.8)	234	35.0 (30.6-39.6)	175	10.2 (8.9-11.7)	201	10.8 (9.3-12.4)
Vision impairment	124	3.5 (2.7-4.4)	6	0.5 (0.2-1.0)	19	1.1 (0.6-1.9)	99	15.0 (11.4-19.3)	49	2.9 (2.0-4.0)	75	4.0 (3.1-5.2)
Hearing impairment	157	4.4 (3.7-5.2)	6	0.5 (0.2-1.2)	35	2.0 (1.4-3.1)	116	17.4 (14.6-20.7)	**71**	**4.2 (3.3-5.3)**	**86**	**4.6 (3.8-5.7)**
Physical impairment	125	3.5 (2.9-4.3)	18	1.5 (0.9-2.3)	24	1.4 (1.0-2.1)	83	12.4 (9.7-15.8)	63	3.7 (3.0-4.6)	62	3.3 (2.5-4.4)
Epilepsy	63	1.8 (1.4-2.2)	13	1.1 (0.6-1.7)	34	2.0 (1.4-3.0)	16	2.4 (1.5-3.8)	33	1.9 (1.4-2.7)	30	1.6 (1.1-2.4)
Depression (>18 ys only)	26	1.1 (0.7-1.6)	-	-	7	0.4 (0.2-1.0)	19	2.8 (1.8-4.6)	9	0.8 (0.4-1.6)	17	1.3 (0.9-2.1)
Multiple impairments	91	2.5 (2.1-3.1)	5	0.4 (0.2-1.0)	10	0.6 (0.3-1.1)	76	11.4 (9.2-13.9)	43	2.5 (1.9-3.4)	48	2.6 (2.0-3.4)
Single Question	**135**	**3.8 (2.9-4.9)**	**27**	**2.2 (1.5-3.3)**	**47**	**2.8 (1.8-4.4)**	**61**	**9.1 (7.0-11.8)**	**71**	**4.2 (3.0-5.8)**	**64**	**3.4 (2.6-4.5)**

*Any disability defined as any significant self-reported limitation or any moderate/severe clinical impairment or health condition

Key Findings:

- Overall prevalence of disability (self-reported significant activity limitation, moderate or severe clinical impairment or disabling health condition) in Telangana State estimated at 12.2% (95% CI 10.6-14.1), which does not vay significantly by gender
- Prevalence increases strongly with age from 3.6% of children under 18, to 8.1% of adults 18-49 and 38.3% of adults 50+
- Overall prevalence of clinical impairments and/or disabling health conditions in Telegana State estimated at 10.5% (95% CI 9.4-11.7) and also increases significantly with age (2.9% of children under 18, 6.3% of adults 18-49 and 35.0% of adults 50+
- Physical impairments (1.5%) and Epilepsy (1.1%) arere most common impairments/health conditions in children, followed by vision (0.5%) and hearing (0.5%). 0.4% of children have multiple impairments/health conditions.
- Hearing impairments (2.0%) and Epilepsy (2.0%) are most common amongst adults 18-49, followed by physical impairments (1.4%), vision impairments (1.1%) and depression (0.4%). Prevalence of multiple impairments is 0.6% in this age group.

- Amongst adults aged 50 and above, 17.4% have hearing impairments, 15.0% have vision impairments, 12.4% have physical impairments, 2.4% Epilepsy and 2.8% depression. 11.4% of this age group have multiple impairments.
- The prevalence of reported significant activity limitations is 7.5% (5.9%-9.4%), and slightly more common in women (8.4% vs 6.5%)
- Prevalence of activity limitations increases in accordance with age from 2.3% of children 2-17, to 4.7% of adults 18-49 and 23.1% of adults 50+
- 41% of participants identified as having a disability screened positive for clinical impairments but did not self-report significant activity limitations. Individuals with moderate clinical impairments in domains such as hearing were less likely to report significant difficulties
- Participants who screened positive for clinical impairments but did not report activity limitations experienced greater participation restrictions than controls, but less than participants who both screened positive for clinical impairments and reported activity limitations
- Children with disabilities are less likely to go to school than children without disabilities (51% vs 91%) and 6 times more likely to have repeated a grade
- Adults with disabilities are less likely to be working (44.4% vs 80.1%) and more likely to have experienced a serious health condition in the previous 12 months than adults without disability
- Adults with disabilities aged 18-49 are nearly 3 times more likely to be in the poorest quarter than adults without disabilities, whilst there is less relationship between poverty and disability amongst adults aged 50+
- Significant participation restrictions and environmental barriers are experienced by children and adults with disabilities of all ages compared to those without disabilities – this includes access to transport, availability of health care services and prejudice and discrimination.
- Awareness of and access to rehabilitation and assistive devices amongst people with disabilities is low, with 12.4% having ever previously received any rehabilitation and 7.7% having received an assistive device.

Photo: Village children leave school for lunch

Conclusions

The study has shown that the prevalence of disability in Telengana State is much higher than previous studies have estimated. The figures suggest that disability is strongly associated with ageing but that the prevalence amongst children and younger adults is still significant. Moreover, the impact of disability is particularly strong amongst children and young adults – limiting access to education and livelihood and significantly linked to poverty.

People with disabilities of all ages are at greater risk of serious health problems, and awareness of and access to rehabilitative services and assistive devices is low.

Recommendations

The following use of the study findings is recommended to policy makers, service providers and other disability advocates and stakeholders:

1) To raise awareness of the prevalence of disability in Telengana State, and specifically the large prevalence of disability and multiple impairments amongst adults aged 50+ who are not eligible for disability benefits
2) To advocate strongly for greater inclusion of children with disabilities in education in Telengana State and particularly to ensuring appropriate methods of education that allow disabled children to progress through school
3) To advocate for better access to health and rehabilitative services amongst children and adults with disabilities in Telengana State, including linking people with disabilities to available services and greater community outreach and support
4) To intensify efforts and advocacy for inclusive societies and services that alleviate the restrictions in participation felt by people with disabilities including barriers in the built and natural environment and as a result of stigma and discrimination
5) To understand the differences in estimates derived from different methodologies of disability measurement, and the most appropriate measures for programs and surveys.

Practical Recommendations on disability data collection:

1) Self-reported tools that measure activity limitation are the most appropriate and resource efficient way to measure disability in a population or within a program or project.
2) Moderate clinical impairments may not be captured using this method, so we recommend that all participants who report even “some” limitation in a particular domain should also undergo a simple clinical screen
3) Measures of participation should also be included to fully capture disability

INTRODUCTION

Background

People with disabilities are often perceived to be among the most marginalized and vulnerable members of society, experiencing substantial inequalities or barriers to accessing many important areas of life including mainstream and rehabilitative health, education, livelihood opportunities and social inclusion.

Few robust quantitative data on disability are available globally.

Reliable statistics on the magnitude and impact of disability are important 1) for planning appropriate, inclusive programs and services for people with disabilities and 2) to raise awareness of the impact of disability and promote full inclusion of persons with disabilities in India. This is to achieve the goals set out in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)[1] which was ratified by India in 2007.

Disability Measurement

The prevailing methodology for disability measurement is via surveys, and there are a number of different approaches to this that focus on different components within disability. Figure 1 presents the International Classification of Functioning, Disability and Health (ICF) Model. This model views disability as the interaction between health conditions and/or impairments in body function and structure, activity limitations caused by the impairment/health condition and the impact on the individual's participation. The relationship between these components is mediated by environmental, personal and contextual factors.

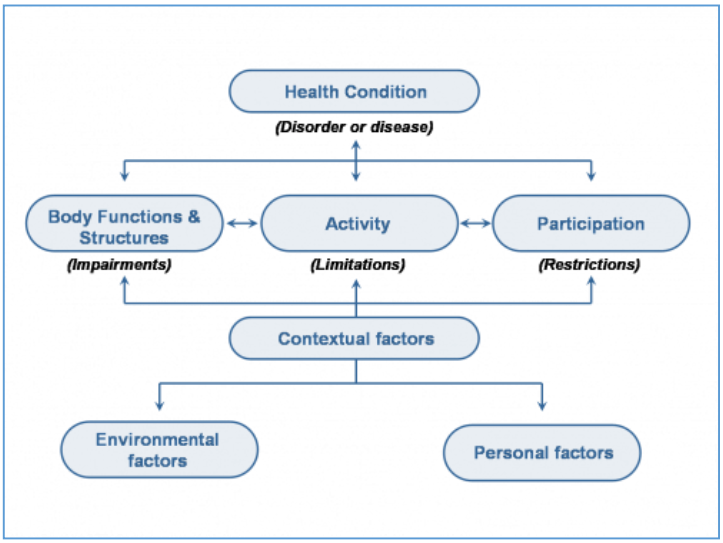


Fig 1: ICF Framework of disability
Source: Rehab-scales.org

Measurement of disability tends to focus on a particular component within the ICF.

Photo: Testing Visual Acuity

Impairments: One approach is to measure specific impairments in body function or structure using objective criteria. Members of ICED have previously been instrumental in developing epidemiological methods for assessment of the prevalence of i) hearing, ii) visual and iii) musculoskeletal impairment [2-4]. Impairment alone is an inadequate proxy for disability since people with the same impairment can experience different types and degrees of activity limitation and participation restriction, depending on the context. However impairment data is essential for planning appropriate and inclusive services amongst competing needs and scare resources.

Activity Limitations: A second approach is self-reported assessment of activity limitations in core domains of function. Domains may include such areas as seeing, hearing, walking, communicating, pain or fatigue, and can be assessed across a severity scale. This approach maximises the information that can be collected at low cost over large populations, and can be aggregated to estimate functioning levels and characteristics across the population[5, 6].

Participation: Several tools have been developed to assess restrictions to participation imposed on the individual by environmental, contextual and personal factors[7].

No previous studies have been undertaken to understand how these concepts inter-relate.

The recent World Report on Disability identified the lack of agreement on the best way to measure disability as a major gap and highlighted the need to develop methods to generate statistics on disability compatible with the World Health Organisation's International Classification of Functioning, Disability and Health framework[8]. This project aims to address this gap through development of a new comprehensive disability survey methodology that includes self-reported measures, impairment measures and participation measures of disability. The project will use this methodology to assess the magnitude and impact of disability in Telengana.

Disability in Telengana

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) was ratified by India on 1st October 2007. The 2011 Census estimates that 2.2% of the Indian population are disabled, however this is widely thought to be an under-estimate.

A 2009 report by Disability Rights Promotion International (DRPI) on disability in Andhra Pradesh states

"The 62 years of Indian Independence has not in any way recognized the issues facing persons with disabilities who are also citizens of this country. One graphic example [is that] neither the central nor the State Governments have the proper statistics as to how many people with disabilities live in this country and state."[9]

Local data are needed on the magnitude of disability, the extent to which people with disabilities are accessing mainstream services and factors that influence this in order to plan appropriate and accessible services and full inclusion of people with disabilities.

Definitions

The study defines a person with a disability as per the United Nations Convention on the Rights of Persons with Disabilities:

People with disabilities include those who have long-term physical, mental and intellectual or sensory impairments which in interaction with various attitudinal and environmental barriers may hinder their full and effective participation in society on an equal basis with others[1].

STUDY AIMS AND OBJECTIVES

Overall Study Aim

To develop and test a best-practice population-based survey methodology to estimate the prevalence of disability in children and adults in India, and to compare the extent to which people with and without disabilities access key mainstream services and opportunities including health, education and livelihoods in Telengana State, India.

Study Objectives

1. To identify a best-practice, comparable and transferable population-based survey methodology that is consistent with the ICF and can assess prevalence of i)Visual, hearing, musculoskeletal impairment and depression ii)Self-reported disability

2. In Telengana State, India:

    i) To undertake a population based survey to estimate the prevalence of impairment and disability
    ii) To explore the extent to which people with disabilities access mainstream health, education, employment and livelihood opportunities in comparison to non-disabled peers
    iii) To identify factors that predict access to health, education, employment and livelihood amongst persons with disabilities
    iv) To Identify barriers and facilitators which mediate access to services

This study is part of a two country study that also includes India. Please visit the ICED website to download the India Report and other resources related to the wider study: http://disabilitycentre.lshtm.ac.uk

METHODS

Study setting

The study was conducted in the Northern half of Mahbubnagar District (estimated district population size: 4,053,028) in Telnngana State. The study worked in partnership with service providers, policy makers and research institutes including the Public Health Foundation of India (PHFI), the Andhra Pradesh Society for Elimination of Rural Poverty (SERP), the Mahbubnagar District Collector's Office Aarogyshri Scheme

Study Design

The study consisted of an all-age population-based random sample, with nested case-control and a qualitative component.

1. Population-based survey:

All survey participants were a) interviewed for self-reported activity limitations and (aged 18+) depression b) screened for visual, hearing and musculoskeletal impairments (all ages). All participants screening positive for clinical impairments were further examined by clinical personnel to determine cause and referred for appropriate health and rehabilitative interventions.

A conservative estimate of 4% disability prevalence, based on previous studies, was used to calculate the sample size for the population-based study. Assuming a precision of 20%, 95% confidence, a design effect of 1.5 and 20% non-response, a sample size of 4056 was calculated. This translated into 51 clusters of 80 people (4080).

2. Nested Case-Control study:

All participants aged ≥5 years who screened positive to either self-reported activity limitations or clinical impairments ('cases') were invited to participate in the nested case-control study. For each case, one age, gender and cluster matched control without a disability was also selected. Cases and Controls were interviewed about socio-demographics, poverty, livelihoods, education, health, water and sanitation, activities and participation. Cases were also asked about perceived cause and history of disability and access to and awareness of rehabilitation services, assistive devices and rights.

An additional one adult and two children with disabilities per cluster were identified via case-finding to ensure that the sample size was sufficient for the nested case-control study to observe differences between cases and controls.

3. Qualitative study:

30 participants identified with disabilities from the population-based sample and the nested case control, plus 14 key informants, were interviewed using a semi-structured questionnaire for the qualitative component. The results of this component of the study are reported separately.

Project preparation

A scoping review of the literature was undertaken to identify self-reported disability tools that have been used in, or been developed for, population-based surveys in LMICs. The Washington Group Extended Set on Functioning for adults, and the Washington Group/UNICEF Draft Child Functioning Tool were selected for use in the survey.

Stakeholders from regional and local government and representatives of civil society were approached for written approval of the study and input into final study design.

Questionnaires were translated into, and back translated from, Telegu to ensure appropriate translation of questions.

Pilot testing of the tools and survey methodology was undertaken in a local, non-enumerated community.

Team Recruitment and Training

Three field teams were recruited and composed of the following:

- 2 Enumerators
- 3 Fieldworkers
- 2 Interviewers
- 1 Vision Technician/Ophthalmic Assistant
- 1 Physiotherapist
- 1 Audiologist (travelling between teams)
- 1 Driver + Car

Photo: Team Training

Field team members underwent an intensive 9 day training on disability awareness and project protocols and methods prior to Pilot Testing.

Selection of Clusters

Clusters were selected using probability proportionate-to-size sampling, whereby clusters (villages) are selected at cumulative population intervals based on total population size and requisite number of clusters. The Indian Census 2011 data was used as the sampling frame. 80 participants were enumerated per cluster. Within clusters, participants were selected using compact segment

sampling conducted by enumerators 1-2 days before the survey. Using existing maps or sketch maps drawn by community members, clusters were divided into segments of approximately 80 people. One segment was then selected at random for inclusion in the survey.

Community Sensitisation, Enumeration and Participant Eligibility

Enumerators first visited the village Sarpanch (village leader) in selected clusters to inform them about the survey and request permission.

A village guide (often an ASHA worker or the Sarpanch) then accompanied the enumerators to the selected segment. At each household, enumerators explained the study purpose and protocol to the household head or an eligible, adult key informant.

If the household head/adult key informant agreed to participate, the enumerator recorded the age, gender and relationship to the household head of all eligible household members[2].

A GPS point-reading and basic observed socio-economic indicators were also recorded.

All eligible household members were then invited to attend the survey screening at a central village location over the following two days. Enumerators visited each house within the segment door-to-door until 80 eligible participants had been recorded.

Photo: Enumeration for population based survey

Population-Based Survey

All participants were given information about the study and asked to give written/finger print consent. A caregiver was also asked to provide onsent for children under 18 years and remain present throughout the screening process.

All participants (>2 years) underwent screening for self-reported activity limitation, followed by clinical screening (all ages) for vision, hearing, musculoskeletal impairment (MSI) and epilepsy. Participants aged 18+ were also screened for clinical depression. Protocols for each screen are described in Table 2. For the full screening questionnaire, refer to Appendix 2.

Proxy respondents were used for all self-reported screens for children aged <8 years and people unable to communicate.

Basic medicines were distributed by clinical team members where appropriate, and all participants with unmet health needs were referred to relevant services.

[2] Eligible household members were defined as any person, any age, who 1) had stayed in the house at least six months of the last year 2) ate shared meals and 3) did not pay rent.

Table 2: Screening Protocol				
	Tool	**Age Group**	**Screen Protocol**	**Examination**
Self-reported activity limitation	Washington Group/UNICEF child functioning module	2-7 8-17	Proxy respondent interviewed on behalf of the child on child's activity limitations (14 questions) Child interviewed directly on their activity limitations (14 questions)	No examination
	Washington Group Extended Set on Functioning for Adults (ES-F)[10]	≥18	Screening Questions on self-reported activity limitations (12 Questions)	No examination
Visual Impairment	Rapid Assessment of Avoidable Blindness[3][11]	0-2 2-4 ≥5	Fix and Follow Finger counting VA testing in both eyes using tumbling 'E' chart with 6/12, 6/18 and 6/60 ototypes. Pinhole testing for all eyes with V/A <6/12	All participants aged ≥5 years with VA <6/12 in either eye or children <5 years who failed the screen examined by a vision technician or ophthalmic assistant using a direct ophthalmoscope to establish main cause of vision loss.
Hearing Impairment	WHO/PBD Ear and Hearing Disorders Examination protocol[2]	0-3 ≥4	Oto-Acoustic Emission Testing Oto-Acoustic Emission Testing and Pure Tone Audiometry	Participants with average hearing loss >35dBa (4-17years) or >41dBa (≥18 years) in either ear examined by an audiologist using an otoscope to determine cause and actions needed.
Musculoskeletal impairment and Epilepsy	Rapid Assessment of Musculoskeletal Impairment (RAM)[4]	0-7 ≥8	Screening Questions on the musculoskeletal system, use of aids and history of seizures directed to proxy respondent (7 Questions) Screening Questions on the musculoskeletal system, use of aids and history of seizures (7 Questions)	Any participant answering yes to at least 1Q examined by a trained physiotherapist. Exam protocol included standardised observation of activities, physical examination, history, diagnosis, aetiology, severity and referral information
Clinical Depression	Patient Health Questionnaire (PHQ9)	≥18	Screening Questions on symptoms and severity (9 Questions)	No examination

[3] The RAAB was initially developed for use in ≥50 year olds and modified for this study with expert input to ensure suitability across all ages

Nested Case-Control Study

All participants ≥5 who screened positive via any of the above screening methods ('cases') were invited to participate in the nested case-control study.

Alongside cases identified via the population-based survey, a further 1 adult and 2 children with disabilities per cluster were identified through case finding, to ensure adequate sample size for the case-control study. Additional cases were identified via key informants from neighbouring segments within the cluster selected for the population survey.

For every case identified, one age, sex and cluster matched control without a disability was also selected from the population-based sample. Controls and cases were matched by age (±3 year for children 5-17 years; ±10 years for adults≥18 years).

i) Eligibility for nested Case-Control study

Cases for the case-control study were restricted to participants aged ≥5years with moderate or severe self-reported limitations or clinical impairments, as defined by international standards and recommendations. Eligibility across the 5 screening tools is outlined in Table 3.

Table 3: Eligibility for Case-Control Study

Self-reported activity limitation	Age 2-17: Response of "a lot of difficulty" or "cannot do at all" in at least one of the following domains: seeing, hearing, walking, self-care, understanding, being understood, learning, remembering
	Aged ≥18: Response of "a lot of difficulty" or "cannot do at all" in at least one of the following domains: seeing, hearing, walking or climbing steps, understanding, being understood, remembering, concentrating, self care, upper body strength, fine motor dexterity
Vision	Visual Acuity <6/18 in better eye with available correction
Hearing	Age 5-17: OAE failure in both ears and PTA reading >35dBa in both ears Aged ≥18: OAE failure in both ears and PTA reading >41dBa in both ears
MSI	Diagnostic Case Confirmation of moderate or severe MSI or epilepsy, based on activity observation and physical examination
Depression	Composite score of 19 or higher

Age and gender matched controls were picked randomly from amongst enumerated participants in the cluster in which no members of the household met the criteria in Table 3.

Modules of the case-control questionnaire included: Socioeconomic indicators, Water and Sanitation, Education (aged <17) Marital Status, Literacy, Education and Livelihood (≥ 18), Health and Antenatal Care, Activity Limitations and Participation Restrictions, Environment

A disability-specific module for cases only included questions on access to/ knowledge of assistive devices, rehabilitative services, inclusive education, inclusive Water and Sanitation and disability benefits.

Referrals and Follow Up

Medical and rehabilitative referral services available in the region were mapped pre-emptively and contacted to guarantee support. Clinical team members provided referrals to partner organisations as appropriate. All identified cases in the study, regardless of health or other need, were given information for the local SERP coordinator and the Aarorgya Mitra Scheme Registry program for additional support in education, health, livelihoods, benefits etc.

Follow up support was provided at the end of the study, with field teams re-contacting all 681 participants who had been offered medical and rehabilitative referrals to provide additional information and offer logistical support. Amongst these, 231 participants were directly assisted in attending follow-up screening.

Data entry and analysis

The Screening Questionnaire results were 1) checked by the team leader for completion in each cluster 2) checked by the project coordinator (IM). Data was double entered into a purpose-built Microsoft Access Database by two trained Data Entry Clerks.

The Case-Control Questionnaire was administered using ASUS Google Nexus 7 tablets. Data collected on each tablet was transferred daily via wifi connection to a cloud based server, with results backed up weekly onto a secured portable hard drive.

Data from both the Screening Questionnaire and the Case-Control Questionnaire were merged in STATA 12.0 for analysis.

Ethical approval

Ethical Approval for the study was granted by:

- The London School of Hygiene and Tropical Medicine (London, UK)
- The Indian Institute of Public Health, Hyderabad Institutional Ethics Committee (India)
- Government of India Health Ministry Screening Committee (India)

Photo: Musculoskeletal examination

RESULTS

Study population and demographics

4,080 people (51 clusters of 80 people) were enumerated for the population-based survey, of whom 3,574 were screened (response rate 88%). Table 4 shows that the age and gender breakdown of the study participants was closely aligned with the demographic structure of the most recent combined Andhra Pradesh Census results (2011).

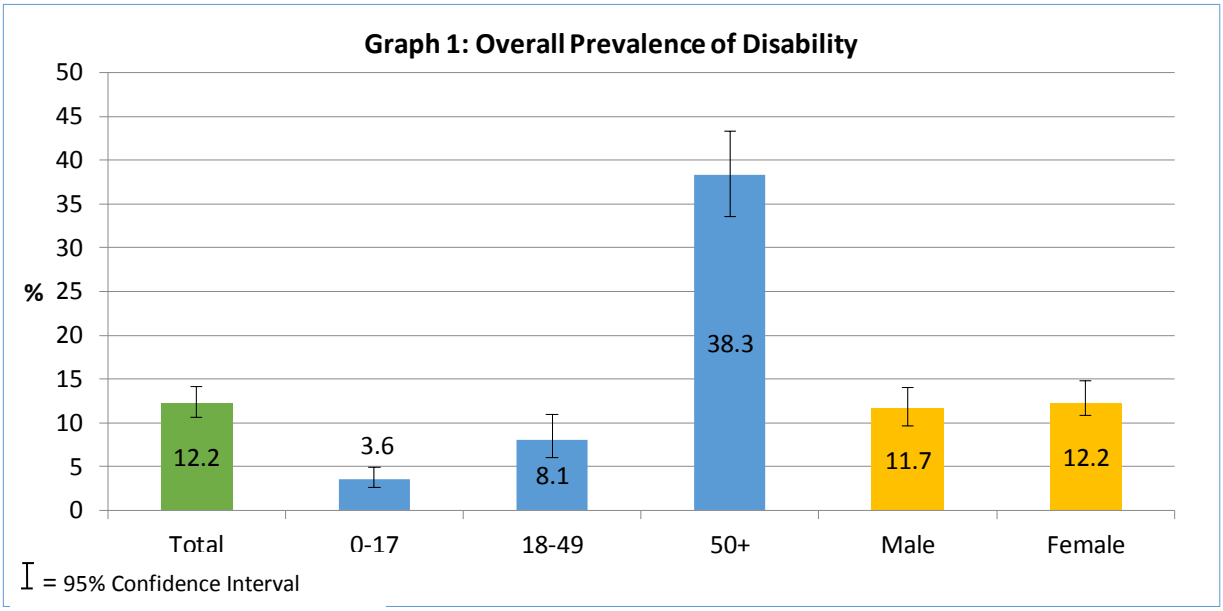
Table 4: Study Population

	Males		Females		Total	
Age group	**District***	**Study sample**	**District***	**Study sample**	**District***	**Study sample**
0-9	6,996,285 (16%)	365 (21%)	6,592,912 (17%)	345 (18%)	13,589,197 17%)	710 (19%)
10-19	8,405,191 (19%)	353 (21%)	7,890,151 (20%)	320 (17%)	16,295,342 (20%)	673 (19%)
20-29	7,865,584 (19%)	277 16%)	8,065,546 (19%)	356 (19%)	15,931,130 (19%)	633 (18%)
30-39	6,498,919 (16%)	214 (13%)	6,592,791 (15%)	284 (15%)	13,091,710 (15%)	498 (14%)
40-49	5,169,031 (12%)	185 (11%)	4,887,711(12%)	207 (11%)	10,056,742 (12%)	392 (11%)
50-59	3,213,122 (8%)	143 (8%)	3,353,862 (8%)	173 (9%)	6,566,984 (8%)	316 (9%)
60-69	2,520,124 (7%)	116 (7%)	2,847,567 (6%)	118 (6%)	5,367,691 (6%)	234 (7%)
70-79	1,060,217 (3%)	42 (2%)	1,096,130 (3%)	46 (2%)	2,156,347 (3%)	88 (2%)
80+	325,987 (1%)	13 (1%)	428,216 (1%)	17 (1%)	754,203 (1%)	30 (1%)
Total	**42,054,460 (50%)**	**1708 (48%)**	**41,754,886 (50%)**	**1866 (52%)**	**83,809,346 (100%)**	**3574 (100%)**

*Indian Census 2011 Andhra Pradesh (Regional) level

Prevalence of Disability

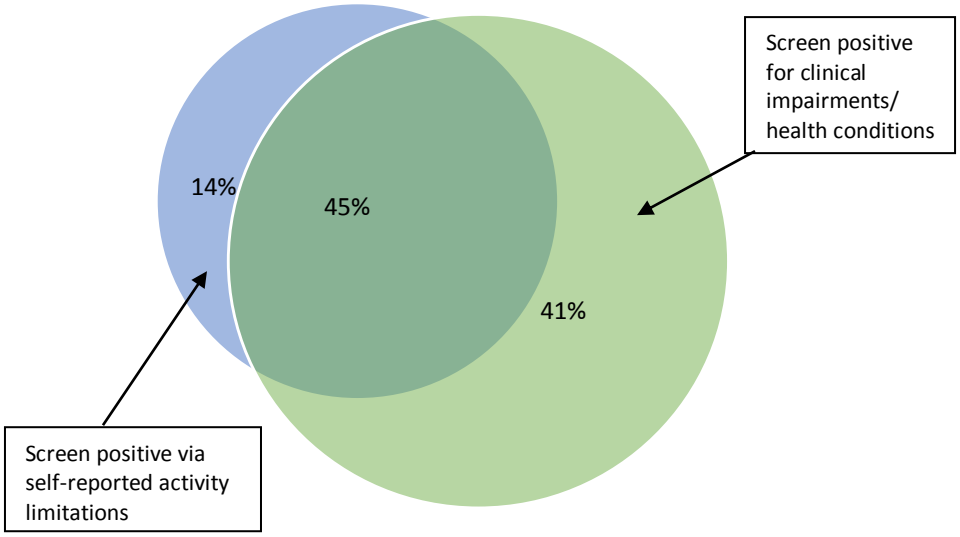
Disability was defined in the sample as any participant reporting a significant activity limitation in any basic activity domain, or screening positive for any moderate or severe clinical impairment, epilepsy or depression (refer back to Table 2 on page 11).



The overall disability prevalence estimate for the sample was 12.2% with no significant difference by gender. There was substantial variation by age group. 3.5% of children 0-17 were defined as having a disability, compared with 8.1% of adults 18-49 and 38.3% of adults aged 50 and above (See Table 21, page 43 for the full breakdown by age and gender).

Amongst those identified to have a disability, 45% both self-reported a limitation and screened positive for a clinical impairment or health condition, 41% screened positive for a clinical impairment but did not self-report a limitation and 14% reported an activity limitation and did not screen positive for a clinical impairment (Fig. 2).

Fig. 2 Relationship between disability measures

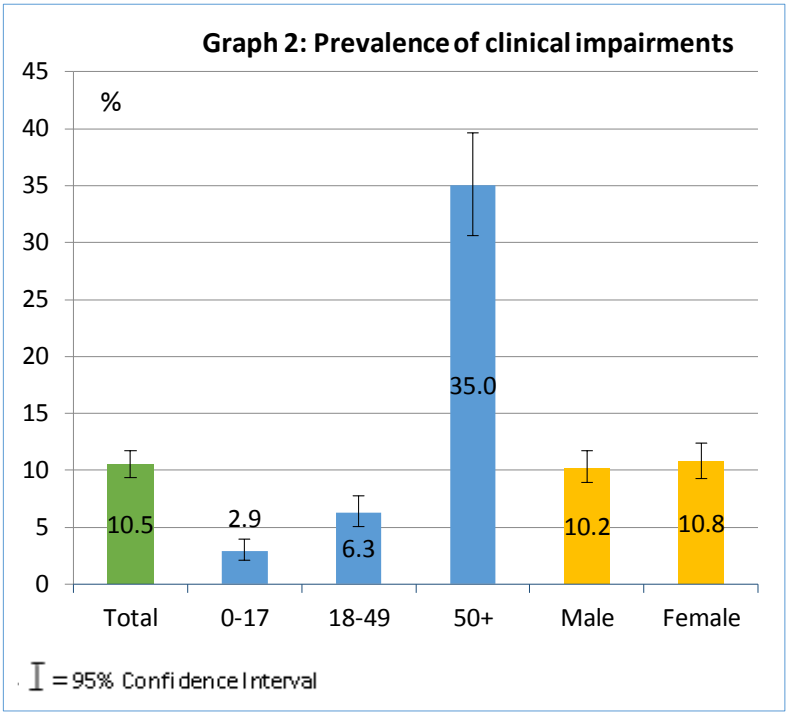


The results over the following pages show disaggregated data 1) amongst those reporting significant activity limitations 2) those screening positive for any moderate or severe clinical impairments, epilepsy and depression 3) on the relationship between the two measures.

Prevalence of clinical Impairments and disabling health conditions

10.5% (95% CI 9.4-11.7) of the study sample screened positive for a moderate or severe clinical impairment in vision, hearing, musculoskeletal impairment (MSI); Epilepsy or clinical depression. Women were slightly more likely to have multiple clinical impairments than men (9.7% vs. 7.9%), but gender ratios were otherwise similar across all impairment types.

The prevalence of clinical impairments and disabling health conditions dramatically increased with age from 2.9% of children 0-17 to 35% of participants over 50 (Graph 2).



Across all ages, 3.5% of the population screened positive for moderate or severe bilateral visual impairment, 4.4% for moderate or severe bilateral hearing impairment, 3.5% for moderate or severe MSI, 1.8% with Epilepsy and 1.1% (amongst adults only) with depression (Table 5, below).

Table 5: Prevalence of Clinical Impairments and health conditions

	Total		0-17 years		18-49 years		50+ years	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Any clinical impairment/ disabling health condition	376	10.5 (9.4-11.7)	36	2.9 (2.1-4.0)	106	6.3 (5.1-7.8)	234	35.0 (30.6-39.6)
Any vision impairment*	124	3.5 (2.7-4.4)	6	0.5 (0.2-1.0)	19	1.1 (0.6-1.9)	99	15.0 (11.4-19.3)
Hearing impairment	157*	4.4 (3.7-5.2)	6	0.5 (0.2-1.2)	35	2.0 (1.4-3.1)	116	17.4 (14.6-20.7)
Physical impairment	125	3.5 (2.9-4.3)	18	1.5 (0.9-2.3)	24	1.4 (1.0-2.1)	83	12.4 (9.7-15.8)
Epilepsy	63	1.8 (1.4-2.2)	13	1.1 (0.6-1.7)	34	2.0 (1.4-3.0)	16	2.4 (1.5-3.8)
Depression (>17 only)	26	1.1 (0.7-1.6)	-	-	7	0.4 (0.2-1.0)	19	2.8 (1.8-4.6)
Multiple	91	2.5 (2.1-3.1)	5	0.4 (0.2-1.0)	10	0.6 (0.3-1.1)	76	11.4 (9.2-13.9)

NB: Data on hearing impairment missing for 11 people (due to discharging ears)
* Estimates of prevalence severity of visual impairment is restricted to participants aged ≥5 years (as VA was not determined for children aged 0-4 years) VA data missing for one person
* Estimates of prevalence of severity of hearing impairment are restricted to those aged >3 years (as severity not determined for children aged 0-3 years). NB data also missing for 2 adults

Clinical impairments in vision, hearing and MSI were graded based on international classifications and recommendations (see Appendix 3 on page 55 for definitions). Impairments graded as "moderate", "severe" or "profound" were included in disability estimates. Table 6 (below) presents the prevalence of vision, hearing and musculoskeletal impairments by severity and age. Profound and severe impairments were less prevalent than moderate impairments across all three impairment types.

Table 6: Severity of Impairments								
	Total		0-17 years		18-49 years		50+ years	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Any clinical impairment/ disabling health condition	376	10.5 (9.4-11.7)	36	2.9 (2.1-4.0)	106	6.3 (5.1-7.8)	234	35.0 (30.6-39.6)
Any vision impairment*	124	3.5 (2.7-4.4)	6	0.5 (0.2-1.0)	19	1.1 (0.6-1.9)	99	15.0 (11.4-19.3)
Moderate	91	2.8 (2.2-3.7)	2*	0.2 (0.06-0.9)	14	0.8 (0.5-1.5)	75	11.3 (8.2-15.2)
Severe	16	0.5 (0.3-0.9)	1	0.1 (0.02-0.86)	3	0.1 (0.06-0.6)	12	1.8 (0.9-3.4)
Blind	14	0.4 (0.2-0.9)	0	0	2	0.1 (0.03-0.5)	12	1.8 (0.9-3.5)
Hearing impairment	157*	4.4 (3.7-5.2)	6	0.5 (0.2-1.2)	35	2.0 (1.4-3.1)	116	17.4 (14.6-20.7)
Moderate	102	3.1 (2.4-3.8)	2	0.1 (0.01-0.8)	14	0.8 (0.4-1.6)	86	12.9 (10.5-15.7)
Severe	34	1.0 (0.7-1.5)	0	0	11	0.7 (0.3-1.2)	23	3.4 (2.2-5.4)
Profound	15	0.5 (0.2-0.9)	0	0	8	0.5 (0.2-1.5)	7	1.0 (0.5-2.4)
Physical impairment	125	3.5 (2.9-4.3)	18	1.5 (0.9-2.3)	24	1.4 (1.0-2.1)	83	12.4 (9.7-15.8)
Moderate	80	2.2 (1.8-2.8)	11	0.9 (0.5-1.6)	16	1.0 (0.6-1.5)	53	7.9 (5.8-10.7)
Severe	44	1.2 (0.8-1.8)	6	0.5 (0.2-1.1)	8	0.5 (0.2-1.0)	30	4.5 (2.9-6.9)

Cause of Clinical Impairments

Cataract was the leading cause of visual impairment, responsible for 74% of all visual impairment (all ages). Refractive error was responsible for 14%, posterior segment diseases for 1% and 12% were undetermined.

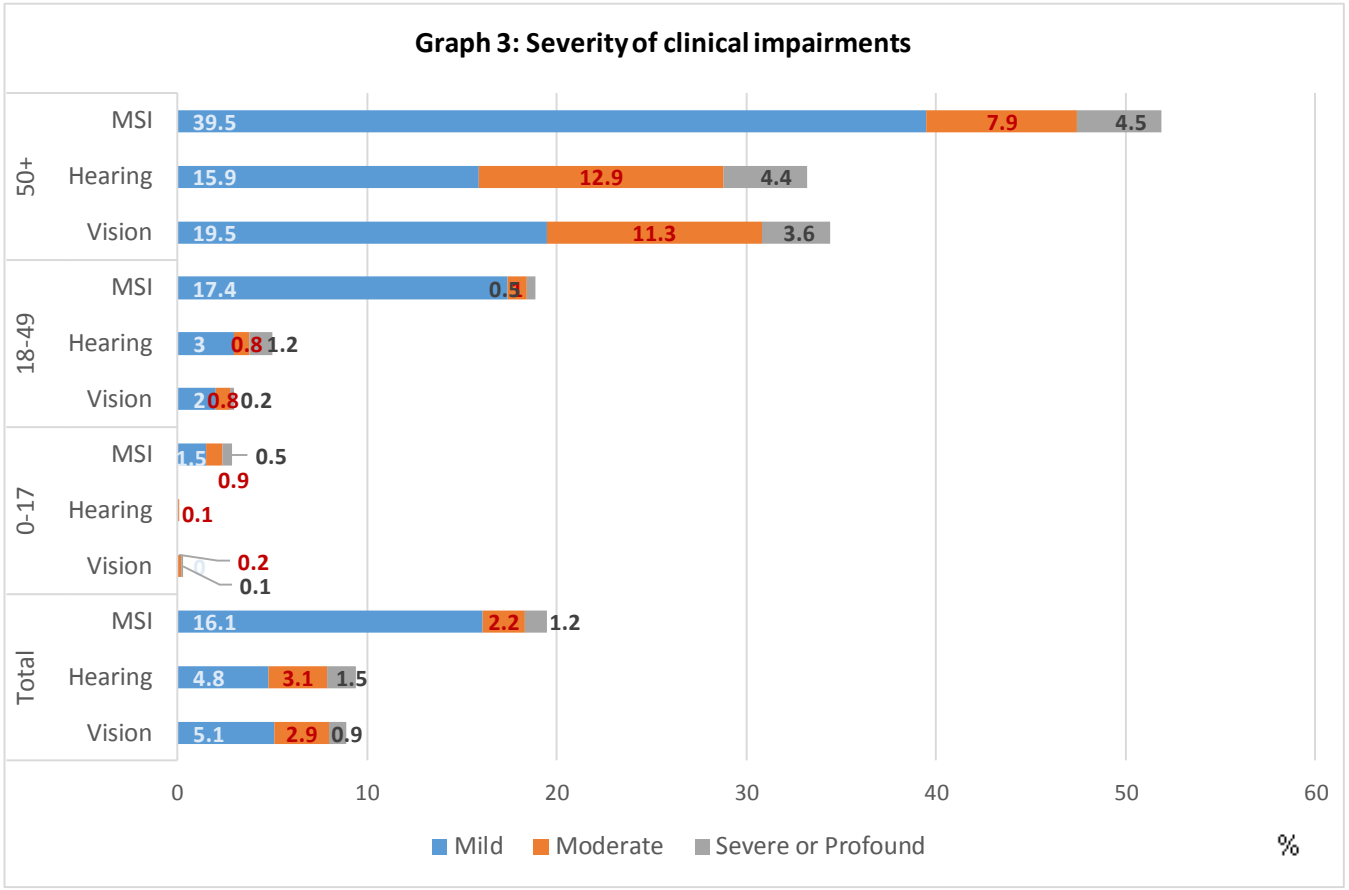
The cause of hearing impairment was unknown for 77 out of 157 people (49%) with hearing impairment. Restricting to those who had cause data, age-related hearing impairment was the leading cause (81%).

Half of moderate and severe physical impairment was due to trauma (Road traffic accidents: 9%, Violence: 5%, Self-harm: 2% and other trauma: 34%) followed by congenital conditions (15%) and aging (15%). Other rarer aetiologies included genetic (3%), infection (3%) developmental (2%), Iatrogenic (2%) and work-related strain (3%). Among children, just over two-thirds of physical impairment was congenital. Among adults aged 18-49 the leading aetiologies were trauma (48%) and congenital (29%). While for older adults trauma (56%) and aging (21%) were the most commonly reported aetiologies.

Inclusion of mild clinical impairments (see Appendix 3 for definitions) in estimates increased the overall prevalence of impairments to 27.7% of the population, and 74.3% of the population aged 50 and above.

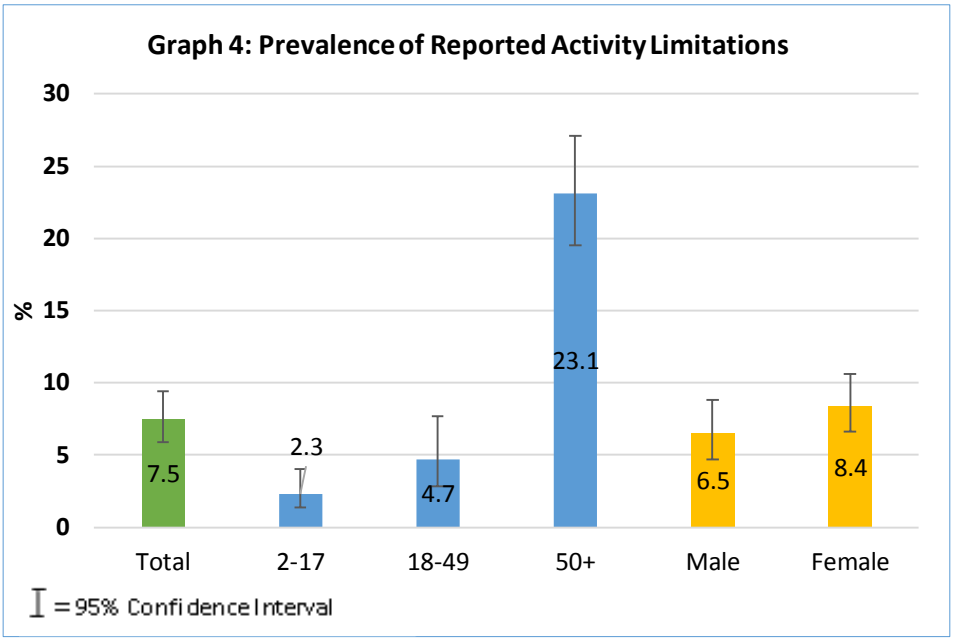
Table 23 on page 45 gives the full breakdown of the prevalence of different impairments (mild, moderate and severe/profound) by gender and age with 95% confidence interval estimates for each.

Graph 3: Severity of clinical impairments



Prevalence of Activity limitations

7.5% (95% CI 5.9-9.4) of the sample (aged 2 and above) were identified as having a disability via reported significant activity limitation (stating "a lot of difficulty" or "unable to do" in at least one basic activity domain).



Significant activity limitation was higher in women than men (8.4% versus 6.5%). Significant activity limitation was also much higher with age, from 2.3% of children 2 to 17, to 4.7% of adults 18 to 49 and 23.1% of adults aged 50 and above (Graph 4).

Amongst children, understanding and learning were the most commonly reported domains in which significant limitations were reported (0.9% each, Graph 5 below), whilst the proportion of children reporting significant limitation in seeing (0.3%) and hearing (0.5%) were lower. Table 7 provides a full breakdown of all children reporting "some difficulty" or"alot of difficulty/cant do" in each basic domain and complex domain.

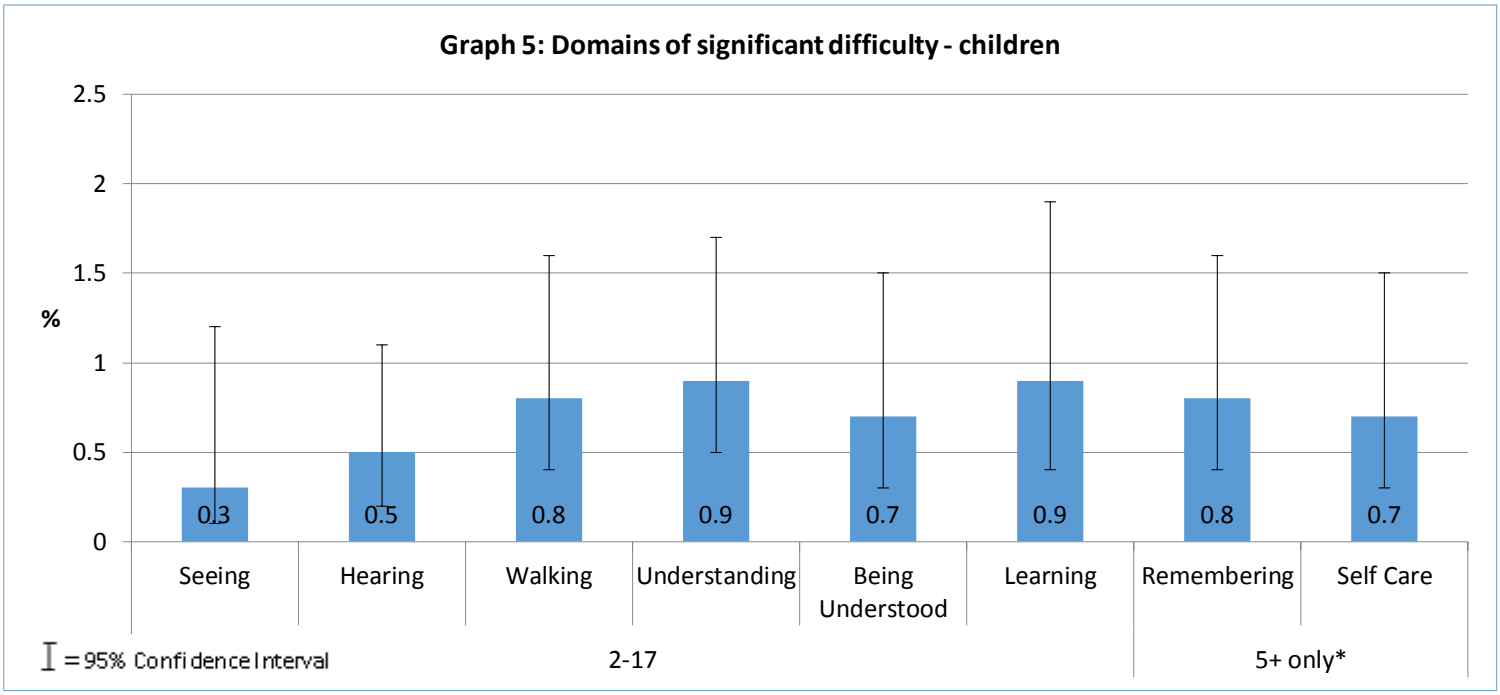
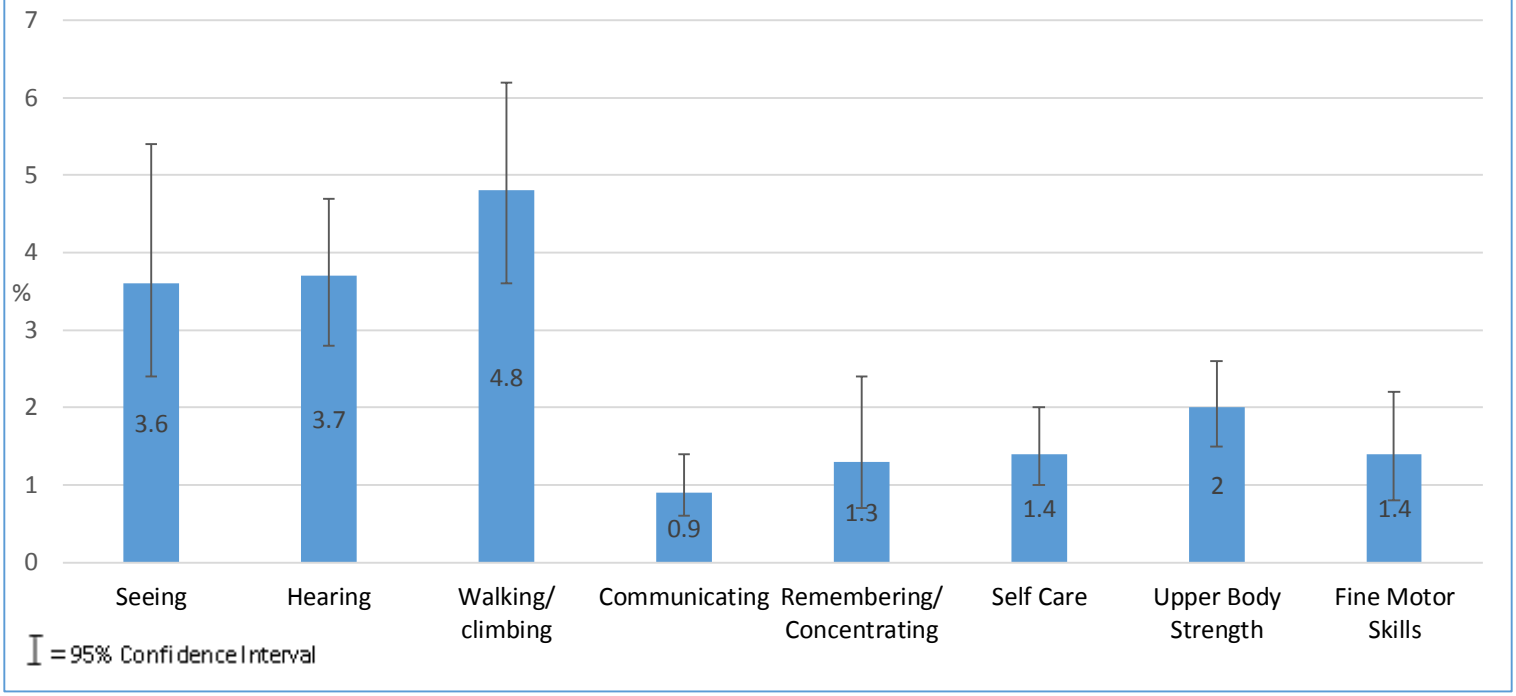


Table 7: proportion of children endorsing activity limitation in each functional domain						
			At least some difficulty		A lot of difficulty/cannot do	
			n	%	n	%
BASIC ACTIVITY DOMAINS	2 to 17	Seeing	46	4.2 (2.7-6.3)	3	0.3 (0.1-1.2)
		Hearing	38	3.5 (2.5-4.7)	5	0.5 (0.2-1.1)
		Walking	39	3.5 (2.5-5.0)	9	0.8 (0.4-1.6)
		Understanding	84	7.6 (5.6-10.4)	10	0.9 (0.5-1.7)
		Being Understood	77	7.0 (5.0-9.6)	8	0.7 (0.3-1.5)
		Learning	125	11.4 (9.3-13.8)	10	0.9 (0.4-1.9)
	5+ only	Remembering	151	17.4 (14.1-21.2)	7	0.8 (0.4-1.6)
		Self Care	33	3.8 (2.5-5.8)	6	0.7 (0.3-1.5)
COMPLEX ACTIVITY/PARTICIPATION DOMAINS	2 to 17	Controlling Behaviour	118	10.7 (8.1-14.0)	11	1.0 (0.5-2.0)
		Playing	54	4.9 (3.3-7.3)	12	1.1 (0.6-2.1)
	5+ only	Worry	59	6.8 (4.7-9.7)	7	0.8 (0.4-1.8)
		Completion of Task	71	8.2 (6.2-10.7)	8	1.0 (0.5-1.8)
		Accept Change	49	5.6 (3.9-8.0)	9	1.0 (0.5-2.1)
		Get along with other children	39	4.5 (2.8-7.0)	9	1.0 (0.5-2.2)

=considered for purposes of study to have a disability

Graph 6: Domains of significant difficulty - adults



Amongst adults, 4.8% reported alot of difficulty in climbing or walking, 3.7% in hearing and 3.6% in vision (Graph 6, above). Table 8 provides a full breakdown of all adults reporting “some difficulty” or”alot of difficulty/cant do” in each basic domain and complex domain.

Table 8: proportion of adults endorsing each domain					
		Some difficulty		A lot of difficulty/cannot do	
		n	%	N	%
Basic Activity Domains	Seeing	805	34.3 (31.4-37.2)	85	3.6 (2.4-5.4)
	Hearing	396	16.9 (15.0-18.8)	86	3.7 (2.8-4.7)
	Walking or climbing	692	29.5 (26.5-32.6)	112	4.8 (3.6-6.2)
	Communicating	180	7.7 (6.0-9.8)	21	0.9 (0.6-1.4)
	Remembering or Concentrating	572	24.4 (21.4-27.5)	31	1.3 (0.7-2.4)
	Self Care	224	9.5 (8.0-11.3)	34	1.4 (1.0-2.0)
	Upper Body Strength	256	10.9 (9.0-13.1)	46	2.0 (1.5-2.6)
	Fine Motor Skills	204	8.7 (6.9-10.8)	32	1.4 (0.8-2.2)
Body Function Domains	Worry	634	27.0 (23.5-30.8)	302	12.9 (10.8-15.3)
	Depression	516	22.0 (18.8-25.5)	235	10.0 (8.2-12.1)
	Pain	888	37.8 (33.7-42.1)	324	13.8 (11.3-16.7)
	Fatigue	920	39.2 (35.4-43.0)	137	5.8 (4.5-7.6)

=considered for purposes of study to have a disability

Relationship between clinical impairments and activity limitations

45% of participants in the study identified to have a disability (n=197) both reported activity limitations and screened positive for moderate or severe clinical impairments and/or disabling health conditions, showing correlation between the two types of tools.

Amongst all of the participants identified to have a disability in the sample, a small proportion (14% of those with disabilities, n=61) screened positive via self-report only. This included 8 children 2-17, 31 adults 18-49 and 22 adults 50+. Of these, 74% were identified with a mild clinical impairment not meeting the definition used to define disability, and the remaining 26% self-reported activity limitations that were not measured clinically (learning, understanding, remembering and self care).

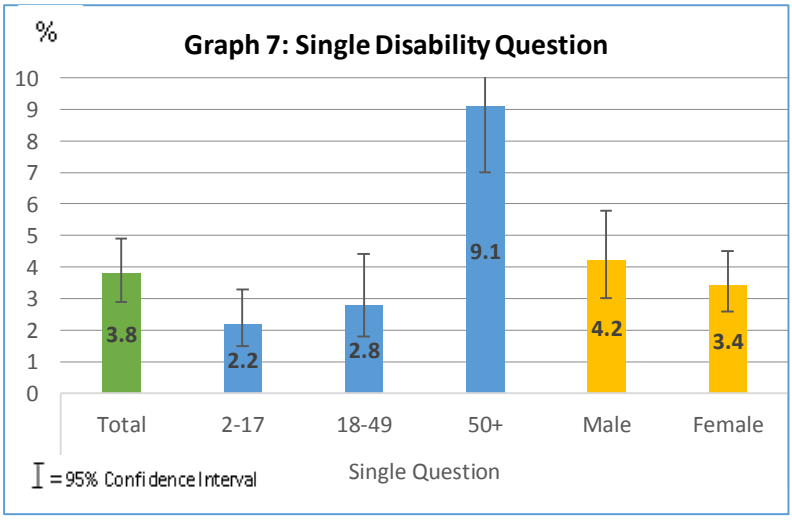
A greater proportion of participants identified to have a disability (41% of those with disabilities, n=178) screened positive for moderate or severe clinical impairments and/or disabling health conditions but did not report significant limitations in these domains in the self-report tool. Amongst this group, 93% of adults and 53% of children reported at least some difficulty in at least one domain (basic or complex).

Multivariate logistic regression, adjusted for gender and age, was undertaken amongst those who screened positive for moderate/severe clinical impairments to understand why some participants did not report significant activity limitations. People who were older (66+) and women were more likely to report significant activity limitations. Clinical cases were more likely to report activity limitations if they had severe or profound impairments rather than moderate impairments. They were also twice as likely to report activity limitations if they had MSI rather than hearing impairments. People with visual impairments or epilepsy were the least likely to report activity limitations, although Epilepsy is not directly screened in the self-reported tool (see Table 9 for Odds Ratios).

Table 9: Odds of Reporting an activity Limitation amongst participants screening positive for clinical impairments					
	Screened +ve for WG (n=197)		Screened -ve for WG (n=176)		Adjusted OR (95% CI)
Age (years)	N	%	N	%	
2-17	17	9	17	10	1.2 (0.5-2.8)
18-33	19	9	21	12	1.3 (0.5-3.1)
34-49	31	16	37	21	1.1 (0.6-2.0)
50-65	72	37	76	43	**baseline**
66+	60	31	25	14	1.9 (1.0-3.5)
Sex					
Male	83	42	90	51	**baseline**
Female	114	58	86	49	1.6 (1.0-2.5)
Severity of impairment					
Moderate	95	48	95	54	**baseline**
Severe	76	39	33	19	2.2 (1.3-3.9)
Profound	22	11	7	4	2.3 (1.0-5.3)
Unknown inc. seizures	4	2	41	23	(omitted)
Type of impairment					
Depression	3	2	4	2	0.3 (0.6-1.7)
Vision	28	14	48	27	0.4 (0.2-0.8)
Musculoskeletal	41	21	16	9.	2.3 1.06-4.8)
Hearing	52	26	43	24.	**baseline**
Epilepsy	4	2	38	22	0.1 (0.03-0.4)
Multiple	69	35	27	15	1.4 (0.7-2.8)

Using a Single Question to Assess Disability Prevalence

A single question, "Do you consider yourself [your child] to have a disability" was included in the screening questionnaire for comparison. Only 30% of those who were identified via self report or clinical screening to have a disability answered "yes" to this question, highlighting the bias of direct questioning approaches (Graph 7). People with disabilities were more likely to answer "yes" if they were younger (2-17 or 18-33), had severe clinical impairments or had MSI.



The Impact of disability on people's lives – A case control study

402 participants from the population-based sample aged 5+ who screened positive for disability, plus an additional 106 individuals with disabilities identified through case-finding (not included in prevalence estimates) were invited to take part in the case-control survey alongside a cluster, age and gender matched control from a household without any persons with disability. The total number of controls is lower than the number of cases because of the unexpectedly large prevalence of disability amongst adults 50+. This limited the number of households available from which to identify controls.

Table 10: Characteristics of Cases and Controls

	Cases (n=508)		Controls (n=337)		Age and Sex adjusted OR
	N	(%)	N	(%)	(95% CI)
Age Group					
5-17	67	13	49	15	(baseline)
18-33	83	16	76	23	0.8 (0.5-1.3)
34-49	94	19	84	25	0.8 (0.5-1.3)
50-65	165	33	111	33	1.1 (0.7-1.7)
66+	99	20	17	5	4.2 (2.2-8.0)
Gender					
Male	231	46	163	48	(baseline)
Female	273	54	174	52	1.1 (0.8-1.4)
SES*					
1st Quartile (poorest)	139	27	60	18	1.7 (1.1-2.6)
2nd Quartile	111	22	92	27	0.9 (0.6-1.3)
3rd Quartile	119	23	89	26	1.0 (0.7-1.5)
4th Quartile (richest)	114	22	85	25	(baseline)
*Some missing data (n=36)					

Table 10 gives the age, gender and socio economic status[4] breakdown of cases and controls. There were more cases than controls in the study due to the high prevalence of disability amongst older age groups and consequent limited number of households without any disability (from which to select eligible controls) in each cluster. Cases and controls were well-balanced on gender. Cases were almost twice as likely to be in the lowest socio-economic status quartile as controls (Adj. OR 1.7, 95% CI 1.1-2.6).

[4] SES scores created using Principal Component Analysis (PCA). PCA index includes asset variables such as household size, construction, water and toilet sources, and durables.

Impact of disability on livelihoods

74.2% of cases and 83.6% of controls aged 18 and above were married or living together. Cases with disabilities were 2.6 times more likely never to have married (95% CI 1.38-4.99).

Very low prior education levels were seen amongst both cases and controls in the study with 65% of adult controls and 73% of adult cases in the sample never having attended school. Consequently literacy was very low in both groups, with 64% of controls and 72% of cases unable to read at all, with no significant difference depending on case-control status (Table 11). Similarly, 73% of controls and 66% of cases mentioned needing to work as the main reason why they had never attended school (Graph 8). 4% of cases said that they did not attend school because of their disability.

Graph 8: Reasons why never attended school

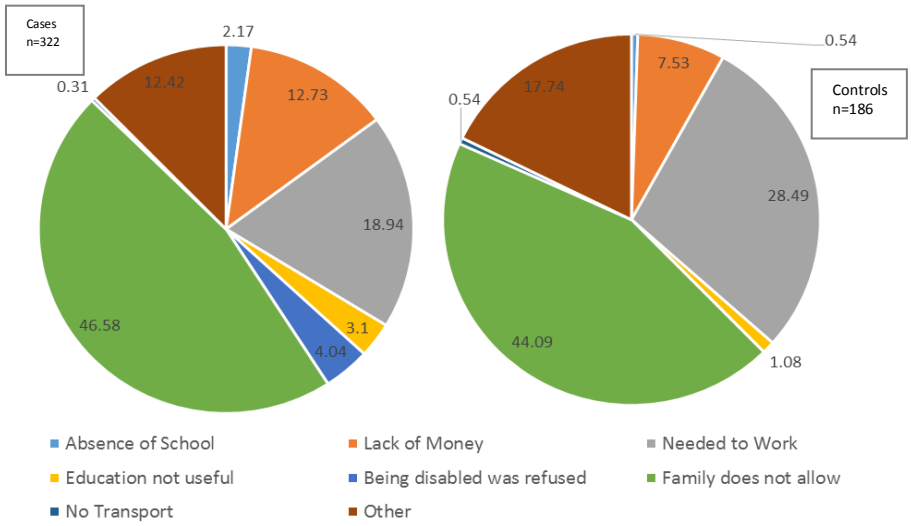


Table 11: Impact of disability on livelihoods					
	Cases		Controls		
	n	%	n	%	Age and Sex Adj OR (95% CI)
Marital Status					
Married or living together	327	74	239	84	(baseline)
Divorced/ Separated	8	2	7	3	0.7 (0.2-2.0)
Widowed	60	14	17	6	1.6 (0.8-2.9)
Never Married/Living together	46	10	23	8	2.6 (1.4-5.0)
Previously attended school					
No	322	73	186	65	(baseline)
Yes	119	27	100	35	0.8 (0.6-1.2)
Literacy					
Read Well	63	14	60	21	0.7 (0.5-1.2)
Read A little	61	14	42	15	1.0 (0.6-1.5)
Not At all	317	72	184	64	(baseline)
Work in the last 7 days					
No	245	56	57	20	4.6 (3.1-6.7)
Yes	196	44	229	80	(baseline)

Cases were almost five times more likely not to have worked in the last 7 days. 80.1% of controls had worked within the prior 7 days, compared with 44.4% of cases (Adj OR 4.6, 95% CI 3.1-6.7). Amongst those not working, 28.4% of cases stated that they were physically incapable of working, compared with 5.7% of controls. Age and retirement was stated as a reason for 45.0% of cases and 37.7% of controls not working.

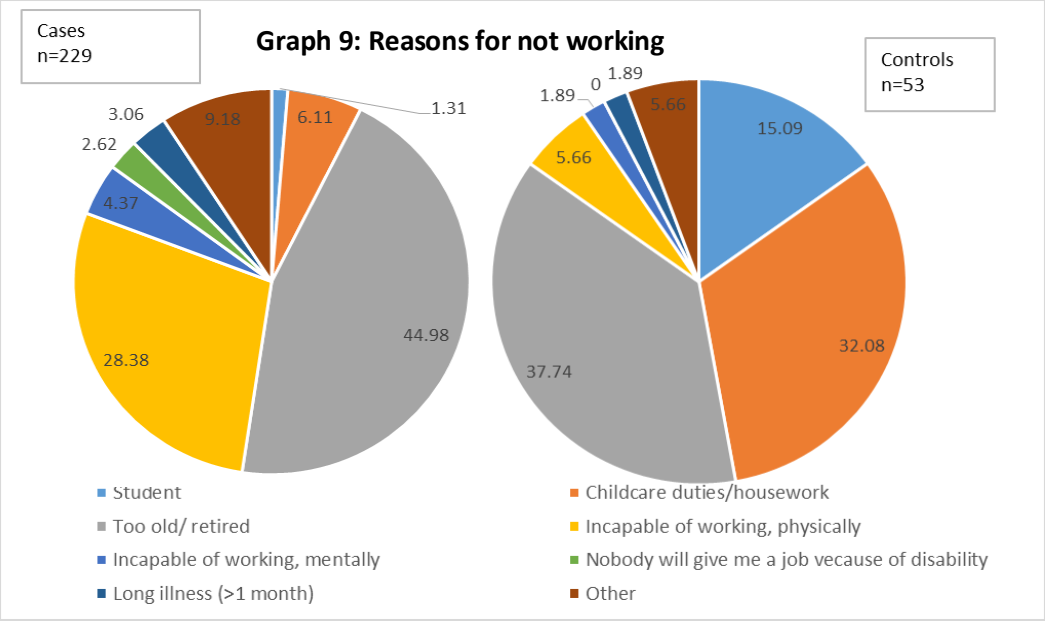


Table 12 presents socio-economic status of cases and controls disagreggated by major age group. There was no significant difference in socio-economic status between cases and controls aged 50 and above but cases aged 18-49 were almost 3 times more likely to be in the poorest quartile (Adj OR. 2.7, 95% CI 1.4-5.2).

Table 12: Socio-economic status by age group*

	Cases		Controls		Age and Sex Adj. OR
	N	%	n	%	(95% CI)
Age 18-49					
1st Quartile (poorest)	50	28	23	14	2.7 (1.4-5.2)
2nd Quartile	33	19	41	26	1.0 (0.5-1.9)
3rd Quartile	45	25	41	26	1.4 (0.8-2.5)
4th Quartile (richest)	39	22	49	31	(baseline)
Age 50+					
1st Quartile (poorest)	72	27	28	22	1.3 (0.7-2.5)
2nd Quartile	61	23	36	28	0.9 (0.5-1.6)
3rd Quartile	62	24	34	27	0.9 (0.5-1.7)
4th Quartile (richest)	58	22	28	22	(baseline)
*Some missing data (n=36)					

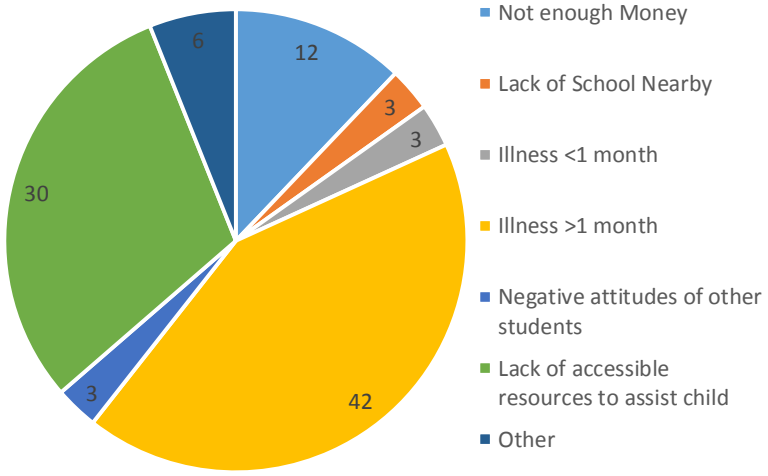
Impact of disability on education among children

67 children with disabilities aged 5 to 17, and 49 cluster, age and gender matched controls participated in the case-control study.

Children with disabilities were more than 10 time more likely not to be enrolled than children without disabilities (51% enrolled vs 91% of controls, Adj. OR 11.1, 95% CI 3.5-33.3). Amongst those children who were enrolled, children with disabilities were almost 6 times more likely to be in a lower grade than other children their age (47% of cases vs 14% of controls, Adj. OR 5.90, 95% CI 1.95-17.88). However, there was no significant difference in the number of days missed in the last month amongst children with and without disabilities enrolled in school.

Amongst the 4 controls not currently enrolled, 2 had previously been enrolled and 2 had never been enrolled. Reasons for not being enrolled were not enough money (n=2) and child working (n=2). Amongst the 33 cases not enrolled, 88% had never attended school, whilst 12% had previously. Main reasons for children with disabilities not attending school were lengthy illness (>1 month) and lack of accessible resources to assist the child's learning (Graph 10).

Graph 10: Reasons for cases not attending school (n=33)



One child with a visual impairment attended a specialist school, all other children with and without disabilities in the sample who were enrolled, were enrolled in mainstream schools.

Table 13: Impact of disability on education

	Cases		Controls		Age and Sex Adj OR (95% CI)
	n	%	n	%	
Currently Enrolled					
No	33	49	4	8	11.1 (3.5-33.3)
Yes	34	51	44	92	(baseline)
Grade					
Same as other children my age	18	53	38	86	(baseline)
Lower than other children my age	16	47	6	14	5.9 (2.0-17.9)
Ever Repeated a Grade					
No	21	62	38	86	baseline
Yes	13	38	6	14	3.9 (1.3-11.8)

Impact of disability on health

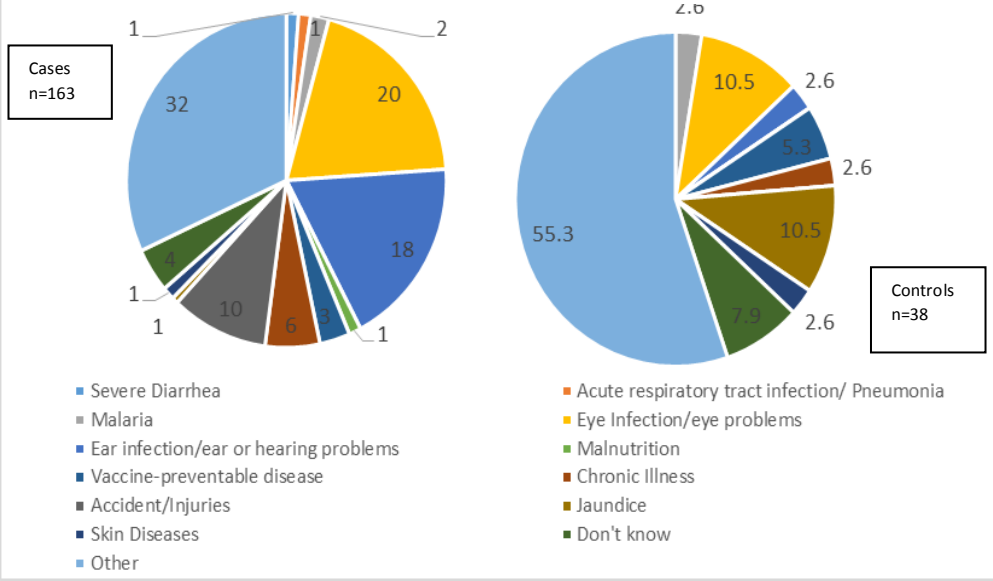
Table 14 presents the age and sex adjusted odds ratios of reported serious health problems amongst cases and controls, disaggregated by age group. 26% of cases and 10% of controls (all ages) had experienced a serious health condition in the preceding 12 months (Adj. OR 3.19, 95% CI 2.10-4.84). The difference in health between cases and controls was most apparent amongst younger cases, with children with disabilities aged 5-17 4.43 more likely to experience have experienced a serious health condition than controls the same age.

Amongst those who had experienced a serious condition, 26% of cases and 15% of controls had experienced more than one in the preceding 12 months. Graph 11 presents the total number of health conditions experienced amongst cases and controls. 20% of health conditions experienced by cases were eye infections, whilst 18% were ear infections. "Other" conditions accounted for 32% of cases and 55% of controls' conditions.

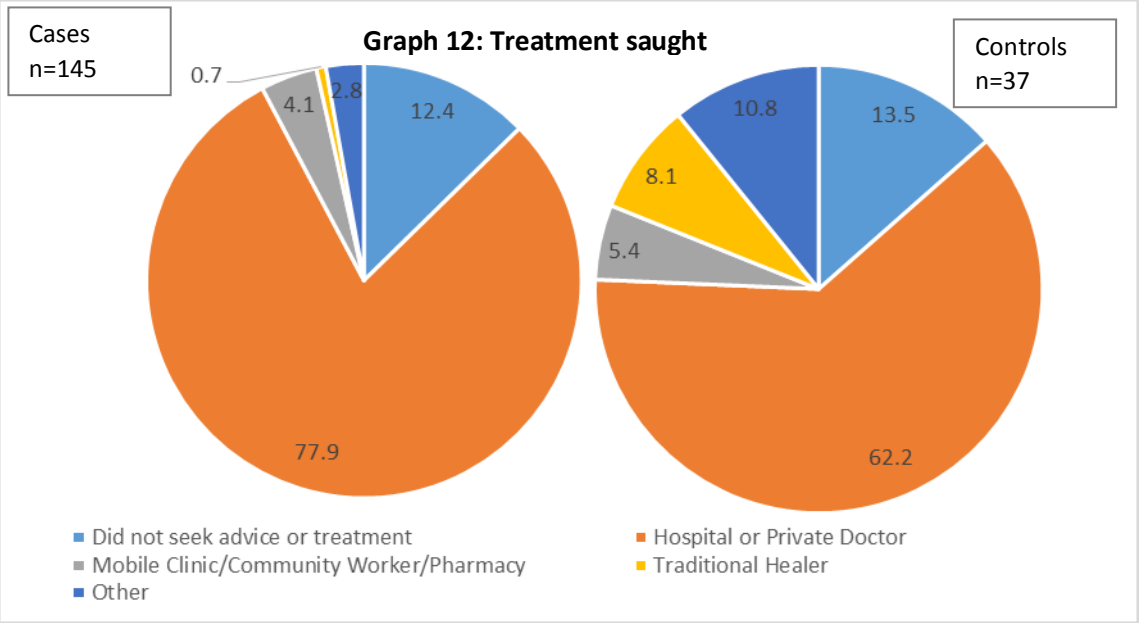
Table 14: Impact of disability on health

	Cases		Controls		Age and Sex Adj OR (95% CI)
	n	%	n	%	
Serious Problem Past 12 Months (total)					
No	378	74	303	90	(baseline)
Yes	130	26	33	10	3.2 (2.1-4.8)
Aged 5-17					
No	52	78	46	94	(baseline)
Yes	15	22	3	6	4.4 (1.2-16.3)
Aged 18-49					
No	133	75	148	93	(baseline)
Yes	44	25	12	8	4.1 (2.1-8.1)
Aged 50+					
No	193	73	109	86	(baseline)
Yes	71	27	18	14	2.4 (1.3-4.3)

Graph 11: Health conditions in last 12 months



77.9% of cases and 62.2% of controls sought medical treatment at a hospital or private doctor for the serious health conditions experienced (graph 12). Similar proportions of cases and controls did not seek any treatment (12.4% of cases and 13.5% of controls) but a greater proportion of controls sought medical attention from a traditional healer than cases (8.1% vs 0.7%).



Impact of disability on Participation and Environmental Access

A question set on participants' abilities to perform a range of activities in their current environment (including with the assistance of any person or assistive device they currently used) was included. The questions covered the domains of self care, domestic life, interpersonal behaviours, major life areas and community/civic life was used to assess participation for cases and controls.

Each question was scored on a response scale of no difficulty, moderate difficulty, severe difficulty and inability to perform activity, and the question sets were differentiated by age[5]. The maximum score for each age group and domain is the total score if each question in the set is answered "unable to do". Table 15 shows the maximum and mean composite participation scores for cases and controls, disaggregated by age. Higher means (i.e. higher participation restrictions) were observed in cases across all age groups, although the difference betweens means lessens with age. An independent-samples t-test was conducted to compare means between cases and controls, and the difference between means was shown to strongly statistically significant in each age group. This shows that persons with disabilities face more participation restrictions than people without disabilities at all ages, but that people without disabilities also experience more participation restrictions with age.

[5] A 5th option, "don't know" is also included. Participants answering "don't know" are not included in the analysis for that particular question

Table 15: Overall Impact of disability on participation					
Age group	Max. score possible	n	Cases (mean)	Controls (mean)	p
Age 5-8	40	43	22.0	12.8	0.01
Age 9-16	60	69	36.44	17.1	<0.001
Age 17-33	81	163	39.8	24.5	<0.001
Age 34-49	75	178	11.7	30.8	<0.001
Age 50-65	81	276	39.8	28.3	<0.001
Age 66+	84	116	49.7	34.6	<0.001

Table 16 disaggregates this data by domain. Both children and adults with disabilities faced greater participation restrictions in all domains than people without disabilities. Restrictions in domestic life (such as preparing meals, doing housework and taking care of others) felt by adults with disabilities were twice as high as those without, as was participation in community, social and civil life amongst children with disabilities (this includes recreation, sports, religious activities).

Table 16: Impact of disability on participation by agegroup and domain					
	Max score possible	n	Cases (mean)	Controls (mean)	p
Children 5-8					
Self Care	20	43	10.5	5.8	<0.01
Interpersonal Behaviours	12	43	6.5	4.1	<0.01
Major Life Areas	5	42	2.6	1.4	<0.001
Community, Social and Civil Life	5	41	2.5	1.3	<0.01
Children 9-16					
Self Care	20	69	10.8	5.1	<0.001
Domestic Life	20	69	15.6	7.4	<0.001
Interpersonal Behaviours	12	69	7	3.4	<0.001
Major Life Areas	5	67	2.5	1.2	<0.001
Community, Social and Civil Life	5	69	2.8	1.2	<0.001
Children and adults 17-49					
Self Care	20	341	6.9	5.3	<0.001
Domestic Life	20	341	19	6.9	<0.001
Interpersonal Behaviours	20	341	8.4	6	<0.001
Major Life Areas	10	341	4.3	2.7	<0.001
Community, Social and Civil Life	15	341	8.5	5.9	<0.001
Children and adults 50+					
Self Care	20	392	8.3	5.4	<0.001
Domestic Life	20	392	13.3	7.9	<0.001
Interpersonal Behaviours	20	392	8.8	6.6	<0.001
Major Life Areas	10	392	5.2	3.6	<0.001
Community, Social and Civil Life	15	392	9.7	6.9	<0.001

12 questions on the frequency at which elements of the built and natural environment created barriers were also asked to both cases and controls. Response categories for each question were 1-Daily, 2- Weekly, 3- Monthly, 4- Less than Monthly, 5-Never, 6-Not Applicable. Excluding responses of N/A, Table17 presents the mean scores for each question for cases and controls, disaggregated by age group and giving the p value of the t-test conducted to compare each mean between cases and controls. The difference between means was strongly statistically significant in each age group, with mean environmental barrier scores lower (corresponding to more frequent barriers in each area) for cases across all environmental areas and each age range than controls. On average, whilst people with disabilities reported more barriers than people without, these were often relatively infrequent – averaging in most domains between monthly and less than monthly.

Table 17: Environmental Access

	5 to 17			18 to 49			50+		
Environmental Domains	Controls (mean) n=49	Cases (mean) n=67	p	Controls (mean) n=160	Cases (mean) n=177	p	Controls (mean) n=128	Cases (mean) n=264	p
Transport	4.8	3.3	<0.001	4.6	3.7	<0.001	4.4	3.4	<0.001
Natural environment	4.9	3.8	<0.001	4.7	4.0	<0.001	4.5	3.8	<0.001
Surroundings	5.0	4.3	<0.001	4.9	4.2	<0.001	4.9	4.1	<0.001
Format of information	5.0	4.0	<0.001	4.8	4.3	<0.001	4.9	4.2	<0.001
Availability of health care services	4.9	3.9	<0.001	4.7	3.9	<0.001	4.5	3.7	<0.001
Availability of assistance at home	4.9	3.8	<0.001	4.8	4.1	<0.001	4.8	3.8	<0.001
Availability of assistance at school	4.9	3.7	<0.001						
Other people's attitudes (at home)	4.9	3.8	<0.001	4.9	4.3	<0.001	4.9	4.1	<0.001
Other people's attitudes (at school)	4.9	3.9	<0.001						
Prejudice and discrimination	4.9	4.0	<0.001	4.9	4.3	<0.001	4.9	4.3	<0.001
Policies and rules (Organisations)	4.9	4.2	<0.01	4.9	4.4	<0.001	4.9	4.4	<0.001
Government programmes and policies	4.9	3.8	<0.001	4.7	4.2	<0.001	4.7	4.1	<0.001

Access to rehabilitation and assistive devices amongst people with disabilities

A module for cases explored access to rehabilitation and assistive devices. Table 18 presents knowledge of, reported need for and access to services amongst cases in the study (n=491). Awareness of services varied between 49.2% stating awareness of general health services and 5.9% reporting awareness of legal advice services. Awareness of core rehabilitative services such as medical rehabilitation (25.7%) and Assistive Devices (32.6%) was relatively low. However, in most instances the majority who needed a particular service reported that they had previously received it.

40.5% of cases in the study reported either not needing or using, or not knowing about any specific assistive devices listed. Glasses were used by 12.4% of the sample and needed (but not used) by a further 12.6%. 19.1% of the sample reported needing a hearing aid, but just 1.2% had access to one.

Table 18: Access to and awareness of rehabilitative services						
	Have heard of services		Have needed services		Have Received Services	
	n	%	n	%	n	%
Medical Rehabilitation	126	26	80	16	61	12
Assistive Device Services	160	33	87	18	38	8
Specialist Educational Services	54	11	26	5	23	5
Vocational Training	49	10	25	5	22	5
Counselling for person with a disability	55	11	25	5	21	4
Counselling for parents/family	59	12	27	6	18	4
Welfare Services	155	32	70	14	48	10
Health Services	240	49	111	23	74	15
Health Information	120	25	64	13	33	7
Traditional or Faith Healers	120	24	31	6	28	6
Legal Advice	29	6	13	3	9	2
Specialist Health Services	106	22	55	11	42	9

Table 19: Access to and awareness of assistive devices								
	Use device		Need but don't use device		Don't need device		Don't know what device is	
	n	%	n	%	n	%	n	%
Glasses	61	12	62	13	326	66	42	9
Magnifying Glass	0	0	3	1	433	88	55	11
White Cane	6	1	2	1	424	86	59	12
Hearing Aid	6	1	94	19	326	66	65	13
Wheelchair	7	1	20	4	400	82	64	13
Crutches	3	1	4	1	422	86	62	13
Walking Stick	79	16	12	2	346	71	54	11
Guide	44	9	7	1	376	77	64	13
Standing Frame	14	3	10	2	399	81	68	14

DISCUSSION

Prevalence of Disability

The overall prevalence of disability in the study was 12.2%, reflecting all participants who either screened positive to self-reported screens of activity limitation (7.5%) or moderate/severe clinical impairments and disabling health conditions (10.5%). This figure is substantially higher than the 2.2% estimated in the Indian Census 2011, and contributes important evidence on disability in Telangana State.

Photo: Testing Hearing Impairment

38.3% of adults aged 50+ were identified to have a disability. This significant increase in disability prevalence by age, including the prevalence of multiple impairments in this age group (11.4%) highlights the need for health and rehabilitative interventions that target older populations and maximise their functioning and wellbeing, especially given trends in population ageing[12]. Many of the limitations faced by older age groups were reversible (e.g. sight loss from cataract) or manageable (e.g. improved joint mobility via physiotherapy). Further work is needed on the relationship between disability and ageing and the potential sense of "inevitability" of function loss that impacts on health-seeking behaviour and leads to large proportions of adults 50+ living with pronounced activity limitations that are reversible or manageable.

The prevalence of clinical impairments in the study was 10.5% (95% CI 9.4-11.7). Similarly, this was strongly associated with age, rising from 2.9% of children 0-17, to 6.3% of adults 18-49 and 35.0% of adults aged 50 and above. A substantial proportion of impairment was treatable or preventable, with the majority of physical impairment due to trauma, hearing impairment due to ageing and visual impairment due to cataract. Improved service delivery and coverage, including community level education on the cause and treatment for clinical impairments, are necessary to eliminate avoidable impairments that can cause significant restrictions on activity and participation.

The self-reported screen also identified large numbers of adults experiencing moderate functional and psychological distress related to worry (27.0%), pain (37.8%) and fatigue (39.2%). Whilst these were not classified as disabilities in the study, they point to important psychological and physical distress amongst the population and warrant further investigation and attention to physchological wellbeing.

Measuring Disability

This study combined three different methods of measuring disability at the population level – a single question ("do you consider yourself to have a disability"), a self-reported activity-limitation tool, and a battery of tools to assess clinical impairments and disabling health conditions in vision, hearing, MSI, epilepsy and clinical depression.

Only 30% of those identified to have a disability via the self-report or clinical tools responded “yes” to the single question on disability. This further substantiates arguments that a single question that asks a person to define themselves as disabled is not an appropriate method of measuring disability in either programs or surveys, and leads to substantial underreport.

Amongst all of those who were identified to have a disability via either self-report or the clinical tools, 45% screened positive for both, 41% screened positive via clinical screens only, and 14% screened positive via self report only. These findings are important, identifying two clear conclusions:

First, that 14% of disability in the study could not be measured using clinical tools. This highlights that impairment tools alone are not sufficient to capture all activity limitations, especially in areas of cognition and mental health.

Second, that 41% of those considered to have a disability in the study did not self-identify as having significant activity limitations. This means that a substantial proportion of people living with moderate or severe clinical impairments do not report “a lot of difficulty” or “can not do” in activities related to that domain (e.g. seeing if visually impaired, hearing if hearing impaired). In particular, individuals with moderate impairments, especially in domains such as hearing, may not report significant difficulties in functioning or activity. Partly, this may be related to the relationship between disability and ageing, as discussed above. Secondly, it may also be related to the perceived “hierarchy” of disability observed in some South-East Asian cultures[13]. Namely, certain impairments, especially in areas of functioning seen to be less critical to the individual’s participation, are not reported. This is shown in that participants with MSI were far more likely to report a significant limitation that participants with vision or hearing impairments, and the connection between MSI and livelihood in a farming community.

Further work is needed in assessing whether self-report tools are appropriate for identifying participants with “severe” disability only, and on whether moderate clinical impairments should be considered to constitute a disability if a participant does not report a limitation in activity, or restriction in participation.

The participation component of disability was also measured in the study, with all cases an controls reporting on participation restrictions and environmental barriers that they experienced. Children and adults with disabilities experienced twice as many restrictions in participation than adults and children without disabilities in all domains measured, and these data are extremely useful to contextualise the lived experience of disability amongst those with activity limitations and impairments.

Table 20 looks at participation restrictions experienced by three groups: 1) people without any clinical impairments or activity limitations, 2) people with both clinical impairments and reported activity limitations and 3) people with clinical impairments who did not report significant activity limitations. The final column gives the p value associated with an independent t test between the means of groups 2 and 3.

Table 20: Participation Restrictions amongst those who do and don't report					
	Max score possible	Controls (mean)	Clinical cases + self report (mean)	Clinical cases no self report (mean)	p
Age 5-8	40	12.8	22.4	18.7	0.59
Age 9-16	60	17.1	39.1	22.6	<0.01
Age 17-33	84	24.5	47.2	28.9	<0.001
Age 34-49	84	30.8	38	32.4	0.07
Age 50-65	84	28.3	43.9	35.4	<0.001
Age 66+	84	34.6	53.5	39.3	<0.001

At each age group, cases faced greater participation restrictions than controls of the same age. However, the level of restriction faced by clinical cases who did not report activity limitations was lower at all age groups than amongst clinical cases who did report limitations. The difference between means was significant at all ages except under 9 years and between 34-49 years. This shows clearly the inter-related components of disability, and how clinical impairments may not necessarily restrict activity and participation to a uniform degree.

Different methodologies for identifying disability amongst populations clearly provide different statistics and within them, different types of information. The most appropriate method to use depends on the reasons for data collection and the resources available. A self-reported tool is the best, and least resource intensive, way to identify those with the highest levels of activity limitations and consequently participation restrictions, but will miss moderate impairments and impairments in domains that are under-prioritised despite the fact that these too cause participation restrictions and can impact on education, livelihoods and health.A best practice therefore, would be the use of a self-reported activity tool to measure the magnitude of signficiant activity limitations in a given population or programme. Alongside this, a simple clinical screen that could be administered to all participants who answer even some difficulty in a specific domain so that all moderate/severe impairments are identified and the appropriate referrals to maximise functioning offered, and a tool to measure and triangulate this with participation restrictions and external barriers that can be addressed and overcome. This recommendation is illustrated in the flow chart below:

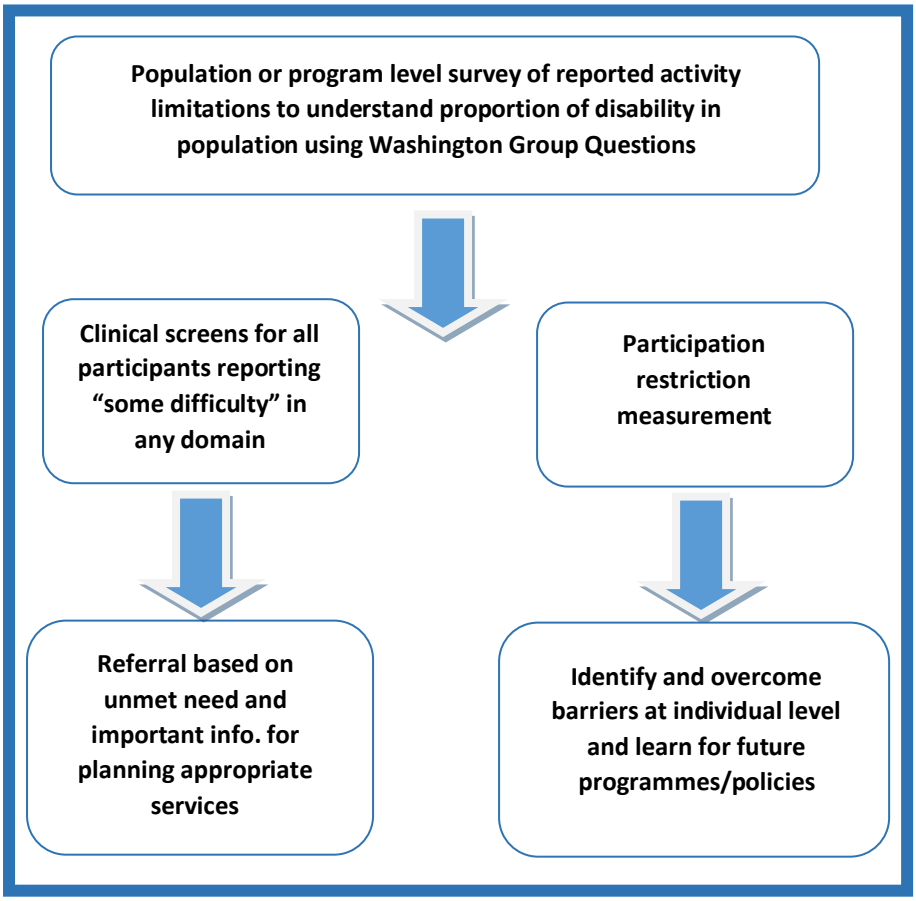


Fig. 3: Disability Measurement Methodology

Impact of Disability on people's lives

Whilst disability prevalence in children was relatively low (3.6%) the impact of disability on the lives of children was high. Children with disabilities were far less likely to be enrolled in education than children without disabilities (51% vs 91% of controls) and those that were enrolled were 6 times more likely to have repeated a grade. This reinforces the findings of previous studies that children with disabilities are still frequently denied education and that even when enrolled do not progress equally to children without disabilities – causing potential disadvantage in later life[14]. Moreover, children with disabilities were over 4 times more likely to have experienced a serious health problem in the previous 12 months than children without disabilities. Children with disabilities also experienced twice as many restrictions to participation in major life areas and community, social and civil life than children without disabilities.

The impact of disability on adults was not significant in certain areas such as prior education and marital status. This is likely due to low socio-economic status and educational attainment across the whole sample (cases and controls) and the high proportion of adults acquiring disability in later life. Moreover, whilst there was no relationship between socio-economic status and disability amongst children and adults over 50+, adults aged 18-49 with disabilities were nearly 3 times more likely to be in the poorest quartile. Whilst this cannot be directly equated to a relationship between age of onset and impact of disability, it does add evidence to the impact of disability if acquired before or during working age, as opposed to in later life[15].

Disability also impacted the likelihood of adults working (significantly lower for cases at 44.4% vs 80.1% of controls) and the likelihood of experiencing a serious health condition (4 times more likely in younger adults and 2.4 times more likely in older adults with disabilities). No differences in health seeking behaviour between people with and without disabilities were observed, but adults with disabilities faced twice as many restrictions in participating in domestic life (such as preparing meals and doing housework) than adults without disabilities.

Photo: Teams checking forms for completion

People with disabilities also faced significant barriers in the natural and built environment, and from stigma and discrimination, at all age groups. This suggests the urgent need for disability mainstreaming and assessment of how to ensure the inclusion of disabled people in mainstream services including via complete accessibility.

Access to services

Awareness of and access to rehabilitative services and assistive devices amongst people with disabilities in study was low, with only 12.4% ever having previously received medical rehabilitation services and 7.7% having previously received an assistive device. These services do exist in Telengana and more work is needed to link those with unmet needs with available service providers. This is particularly important given the large magnitude of MSI and hearing impairment amongst those aged 50 and above.

How can this information be used?

The prevalence estimates of disability, self-reported limitations and clinical impairments are of great use to policy makers, service providers and disability advocates in India. Moreover, these data contribute to the limited evidence base on disability globally.

The case-control study provides important data on the impact of disability, most notably on children's participation and on the strong relationship between disability and poor health, and disability and participation restriction.

The comparison of estimates using different tools adds important findings to international disability data collection methods and understanding the interaction between different components of disability – namely impairments in body function and structure, activity limitations and participation restrictions.

Strengths and weaknesses

Strengths:

The study used a robust and scientifically valid sampling methodology to provide vigorous estimates of disability compatible with the ICF. The study measured and compared the relationship between different components of disability and provided much needed information on the impact of disability on access to services and participation in Telengana.

Weaknesses:

The study case-control matching was compromised by the unexpectedly large prevalence of disability in older age groups. This meant that a small number of households per cluster did not contain at least one person with a disability.

It is also acknowledged that Case-finding additional cases with disability from neighbouring segments for the case control study is likely to identify individuals with more 'obvious' and severe disabilities, and potentially missed those with more hidden impairments such as mild/moderate cognitive or hearing impairments.

Tools and diagnostic tests for mental health in this study were limited, and further work is needed on incorporating screening methodologies for mental health into disability measurement tools.

Conclusions

The study has shown that the prevalence of disability in Telangana State, Mahabubnagar district, is much higher than previous studies have estimated. The figures suggest that disability is strongly associated with ageing but that the prevalence amongst children and younger adults is still important. Moreover, the impact of disability is particularly strong amongst children and young adults. People with disabilities of all ages are at greater risk of serious health problems, and awareness of and access to rehabilitative services and assistive devices is low.

The study has also provided clear evidence on the different components of disability as measured by different tools, and the information that is and is not captured using different methodologies. It is hoped that these findings will provide clarity on how and why to measure disability in a way that is comprehensive and comparable.

Recommendations

The following use of the study findings is recommended to policy makers, service providers and other disability advocates and stakeholders:

1. To raise awareness of the prevalence of disability in Telegana State, and specifically the large prevalence of disability and multiple impairments amongst adults aged 50+
2. To advocate strongly for greater inclusion of children with disabilities in education and particularly to ensuring appropriate methods of education that allow disabled children to progress through school

3. To advocate for better access to health and rehabilitative services amongst children and adults with disabilities, including linking people with disabilities to available services and greater community outreach and support
4. To intensify efforts and advocacy for inclusive societies and services that alleviate the restrictions in participation felt by people with disabilities
5. To understand the differences in estimates derived from different methodologies of disability measurement, and to consider a comprehensive methodlogy that incorporates the core components of clinical impairments, activity limitations and participation restrictions.

Practical Recommendations on disability data collection

1. Self Reported tools that measure ativity limitation are the most appropriate and resource efficient way to measure disability in a population or within a program or project.
2. Moderate clinical impairments may not be captured using this method, so we recommend that all participants who report even "some" limitation in a particular domain should also undergo a simple clinical screen
3. Measures of participation should also be included to fully capture disability.

Stakeholder Response

Dissemination sessions were held in November 2014 in Hyderabad and Mahbubnagar, to share the findings with key stakeholders and finalise the recommendations. Workshops were attended by high-level government representatives including the CEO of SERP and the Mahbubnagar District Collector. Workshops were also well attended by NGOs, DPO representatives, public health researchers and private service providers. A clear outcome from the two workshops was the call for stakeholders from all sectors to converge and create a platform for regular discussion and coordination of activites to maximise opportunities and access to services amongst people with disabilities in Telengana State. A focus on ensuring that people had access to information on available services was also suggested.The CEO of SERP in particular pledged that SERP services would focus on building confidence amongst people with disabilities and advocating for attitudinal change.

The study findings were overall praised for providing much needed evidence on the impact of disability on people's lives, and the study's intention to provide community feedback sessions between Dec 2014-Jan 2015 was commended.

Table 21: Overall Prevalence of Disability by age and gender												
	Total		0-17 years*		18-49 years		50+ years		Male		Female	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Any disability	**437**	**12.2 (10.6-14.1)**	**44**	**3.6 (2.6-4.9)**	**137**	**8.1 (6.0-11.0)**	**256**	**38.3 (33.6-43.3)**	**199**	**11.7 (9.7-14.0)**	**238**	**12.2 (10.9-14.8)**
Self Reported Limitations	258	7.5 (5.9-9.4)	25	2.3 (1.4-3.7)	79	4.7 (2.8-7.7)	154	23.1 (19.5-27.1)	107	6.5 (4.7-8.8)	151	8.4 (6.6-10.6)
Any moderate or severe impairment or disabling health condition	376	10.5 (9.4-11.7)	36	2.9 (2.1-4.0)	106	6.3 (5.1-7.8)	234	35.0 (30.6-39.6)	175	10.2 (8.9-11.7)	201	10.8 (9.3-12.4)
Any vision impairment*	124	3.5 (2.7-4.4)	6	0.5 (0.2-1.0)	19	1.1 (0.6-1.9)	99	15.0 (11.4-19.3)	49	2.9 (2.0-4.0)	75	4.0 (3.1-5.2)
Moderate	91	2.8 (2.2-3.7)	2*	0.2 (0.06-0.9)	14	0.8 (0.5-1.5)	75	11.3 (8.2-15.2)	40	2.6 (1.7-3.9)	51	3.0 (2.3-4.1)
Severe	16	0.5 (0.3-0.9)	1	0.1 (0.02-0.86)	3	0.1 (0.06-0.6)	12	1.8 (0.9-3.4)	3	0.2 (0.06-0.6)	13	0.8 (0.4-1.4)
Blind	14	0.4 (0.2-0.9)	0	0	2	0.1 (0.03-0.5)	12	1.8 (0.9-3.5)	5	0.3 (0.1-0.9)	9	0.5 (0.3-1.1)
Hearing impairment	157*	4.4 (3.7-5.2)	6	0.5 (0.2-1.2)	35	2.0 (1.4-3.1)	116	17.4 (14.6-20.7)	71	4.2 (3.3-5.3)	86	4.6 (3.8-5.7)
Moderate	102	3.1 (2.4-3.8)	2	0.1 (0.01-0.8)	14	0.8 (0.4-1.6)	86	12.9 (10.5-15.7)	46	2.7 (1.9-3.7)	56	3.0 (2.3-3.9)
Severe	34	1.0 (0.7-1.5)	0	0	11	0.7 (0.3-1.2)	23	3.4 (2.2-5.4)	14	0.8 (0.4-1.7)	20	1.1 (0.7-1.6)
Profound	15	0.5 (0.2-0.9)	0	0	8	0.5 (0.2-1.5)	7	1.0 (0.5-2.4)	7	0.4 (0.1-1.1)	8	0.4 (0.2-0.9)
Physical impairment	125	3.5 (2.9-4.3)	18	1.5 (0.9-2.3)	24	1.4 (1.0-2.1)	83	12.4 (9.7-15.8)	63	3.7 (3.0-4.6)	62	3.3 (2.5-4.4)
Moderate	80	2.2 (1.8-2.8)	11	0.9 (0.5-1.6)	16	1.0 (0.6-1.5)	53	7.9 (5.8-10.7)	41	2.4 (1.8-3.2)	39	2.1 (1.5-2.9)
Severe	44	1.2 (0.8-1.8)	6	0.5 (0.2-1.1)	8	0.5 (0.2-1.0)	30	4.5 (2.9-6.9)	22	1.3 (0.8-2.1)	22	1.2 (0.7-1.9)
Epilepsy	63	1.8 (1.4-2.2)	13	1.1 (0.6-1.7)	34	2.0 (1.4-3.0)	16	2.4 (1.5-3.8)	33	1.9 (1.4-2.7)	30	1.6 (1.1-2.4)
Depression (>18 ys only)	26	1.1 (0.7-1.6)	-	-	7	0.4 (0.2-1.0)	19	2.8 (1.8-4.6)	9	0.8 (0.4-1.6)	17	1.3 (0.9-2.1)
Multiple	91	2.5 (2.1-3.1)	5	0.4 (0.2-1.0)	10	0.6 (0.3-1.1)	76	11.4 (9.2-13.9)	43	2.5 (1.9-3.4)	48	2.6 (2.0-3.4)
Single Question	**135**	**3.8 (2.9-4.9)**	**27**	**2.2 (1.5-3.3)**	**47**	**2.8 (1.8-4.4)**	**61**	**9.1 (7.0-11.8)**	**71**	**4.2 (3.0-5.8)**	**64**	**3.4 (2.6-4.5)**

Table 22: Prevalence of activity limitations in adults by domain, age and gender											
		Total		18-49 years		50+ years		Male		Female	
		N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
No basic domains scored "a lot of difficulty" or "can't do"		2116	90.1 (87.6-92.1)	1603	95.3 (92.3-97.2)	513	76.9 (72.9-80.5)	977	91.1 (87.9-93.5)	1139	89.3 (86.5-91.5)
At least one basic domain "a lot of difficulty" or "can't do"		233	9.9 (7.9-12.4)	79	4.7 (2.8-7.7)	154	23.1 (19.5-27.1)	96	8.9 (6.5-12.1)	137	10.7 (8.5-13.5)
At least one complex domain scored "somewhere between a little and a lot" or "a lot"		687	29.2 (26.5-32.2)	422	25.1 (22.2-28.2)	265	39.7 (35.1-44.6)	276	25.7 (22.6-29.1)	411	32.2 (28.6-36.0)
Basic Activity Domains	Seeing	85	3.6 (2.4-5.4)	26	1.5 (0.7-3.6)	59	8.8 (6.5-12.0)	23	2.1 (1.0-4.3)	62	4.9 (3.4-6.9)
	Hearing	86	3.7 (2.8-4.7)	25	1.5 (0.9-2.5)	61	9.1 (6.6-12.5)	35	3.3 (2.2-4.8)	51	4.0 (3.0-5.3)
	Walking or climbing	112	4.8 (3.6-6.2)	24	1.4 (0.6-3.1)	88	13.2 (10.6-16.3)	46	4.3 (2.7-6.7)	66	5.2 (4.0-6.8)
	Communicating	21	0.9 (0.6-1.4)	10	0.6 (0.3-1.2)	11	1.6 (0.9-3.0)	8	0.7 (0.4-1.4)	13	0.1 (0.6-1.8)
	Remembering or Concentrating	31	1.3 (0.7-2.4)	20	1.2 (0.5-2.7)	11	1.6 (0.8-3.3)	10	0.9 (0.4-2.1)	21	1.6 (0.9-3.1)
	Self Care	34	1.4 (1.0-2.0)	4	0.2 (0.1-0.6)	30	4.5 (3.0-6.7)	13	1.2 (0.7-2.1)	21	1.6 (1.1-2.5)
	Upper Body Strength	46	2.0 (1.5-2.6)	7	0.4 (0.2-0.9)	39	5.8 (4.3-8.0)	17	1.6 (1.0-2.6)	29	2.3 (1.6-3.2)
	Fine Motor Skills	32	1.4 (0.8-2.2)	10	0.6 (0.2-2.0)	22	3.3 (2.2-4.9)	16	1.5 (0.7-3.0)	16	1.3 (0.8-2.0)
Body Function Domains	Worry	302	12.9 (10.8-15.3)	175	10.4 (8.3-13.0)	127	19.0 (15.7-23.0)	116	10.8 (8.4-13.7)	186	14.6 (12.1-17.4)
	Depression	235	10.0 (8.2-12.1)	133	7.9 (6.3-9.9)	102	15.3 (12.2-18.9)	92	8.6 (6.6-11.1)	143	11.2 (9.1-13.8)
	Pain	324	13.8 (11.3-16.7)	202	12.0 (9.7-14.8)	122	18.3 (13.9-23.6)	137	12.8 (10.1-16.0)	187	14.7 (12.0-17.8)
	Fatigue	137	5.8 (4.5-7.6)	76	4.5 (3.3-6.2)	61	9.1 (6.7-12.3)	55	5.1 (3.7-7.0)	82	6.4 (4.6-8.8)

Table 23: Prevalence of mild, moderate and severe clinical impairments												
	Total		**0-17 years***		**18-49 years**		**50+ years**		**Male**		**Female**	
	N	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**	**N**	**% (95% CI)**
Any Mild, Moderate or Severe Clinical impairment	988	27.7 (25.1-30.4)	54	4.4 (2.3-6.0)	438	26.0 (21.9-30.6)	496	74.3 (68.9-79.0)	435	25.5 (22.5-28.7)	553	29.6 (26.6-32.8)
Any Moderate or Severe impairment	376	10.5 (9.4-11.7)	36	2.9 (2.1-4.0)	106	6.3 (5.1-7.8)	234	35.0 (30.6-39.6)	175	10.2 (8.9-11.7)	201	10.8 (9.3-12.4)
Any vision impairment*	284	8.9 (7.6-10.4)	3	0.4 (0.1-1.1)	53	3.2 (2.2-4.5)	228	3.5 (3.0-3.9)	119	7.8 (6.3-9.6)	165	9.9 (8.5-11.6)
Mild	163	5.1 (4.2-6.3)	0	0	34	2.0 (1.3-3.1)	129	19.5 (16.1-23.5)	71	4.7 (3.5-6.1)	92	5.5 (4.5-6.8)
Moderate	91	2.9 (2.2-3.7)	2*	0.2 (0.06-0.9)	14	0.8 (0.5-1.5)	75	11.3 (8.2-15.2)	40	2.6 (1.7-3.9)	51	3.0 (2.3-4.1)
Severe	16	0.5 (0.3-0.9)	1	0.1 (0.02-0.86)	3	0.1 (0.06-0.6)	12	1.8 (0.9-3.4)	3	0.2 (0.06-0.6)	13	0.8 (0.4-1.4)
Blind	14	0.4 (0.2-0.9)	0	0	2	0.1 (0.03-0.5)	12	1.8 (0.9-3.5)	5	0.3 (0.1-0.9)	9	0.5 (0.3-1.1)
Hearing impairment	308	9.3 (7.9-11.0)	2	0.1 (0.01-0.8)	84	5.0 (3.7-6.8)	222	3.3 (2.9-3.8)	145	8.5 (7.0-10.3)	163	8.7 (7.1-10.6)
Mild	157	4.8 (3.8-6.0)	0	0	51	3.0 (2.1-4.3)	106	15.9 (12.6-19.8)	78	4.6 (3.6-5.8)	79	4.2 (3.0-5.9)
Moderate	102	3.1 (2.4-3.8)	2	0.1 (0.01-0.8)	14	0.8 (0.4-1.6)	86	12.9 (10.5-15.7)	46	2.7 (1.9-3.7)	56	3.0 (2.3-3.9)
Severe	34	1.0 (0.7-1.5)	0	0	11	0.7 (0.3-1.2)	23	3.4 (2.2-5.4)	14	0.8 (0.4-1.7)	20	1.1 (0.7-1.6)
Profound	15	0.5 (0.2-0.9)	0	0	8	0.5 (0.2-1.5)	7	1.0 (0.5-2.4)	7	0.4 (0.1-1.1)	8	0.4 (0.2-0.9)
Physical impairment	698	19.5 (16.7-22.7)	35	2.9 (1.9-4.2)	316	18.8 (15.0-23.3)	347	51.9 (44.7-59.1)	292	17.1 (14.2-20.4)	406	21.8 (18.5-25.4)
Mild	574	16.1 (13.3-19.2)	18	1.5 (0.8-2.6)	292	17.4 (13.8-21.7)	264	39.5 (32.8-46.7)	229	13.4 (10.7-16.6)	345	18.5 (15.3-22.2)
Moderate	80	2.2 (1.8-2.8)	11	0.9 (0.5-1.6)	16	1.0 (0.6-1.5)	53	7.9 (5.8-10.7)	41	2.4 (1.8-3.2)	39	2.1 (1.5-2.9)
Severe	44	1.2 (0.8-1.8)	6	0.5 (0.2-1.1)	8	0.5 (0.2-1.0)	30	4.5 (2.9-6.9)	22	1.3 (0.8-2.1)	22	1.2 (0.7-1.9)
Epilepsy	63	1.8 (1.4-2.2)	13	1.1 (0.6-1.7)	34	2.0 (1.4-3.0)	16	2.4 (1.5-3.8)	33	1.9 (1.4-2.7)	30	1.6 (1.1-2.4)
Depression (>18 ys only)	26	1.1 (0.7-1.6)	-	-	7	0.4 (0.2-1.0)	19	2.8 (1.8-4.6)	9	0.8 (0.4-1.6)	17	1.3 (0.9-2.1)
Multiple	316	8.8 (7.8-10.0)	7	0.6 (0.3-1.3)	52	3.1 (2.1-4.5)	257	3.8 (3.4-4.3)	135	7.9 (6.8-9.2)	181	9.7 (8.3-11.3)

NB: Data on hearing impairment missing for 11 people (due to discharging ears)

* Estimates of prevalence severity of visual impairment is restricted to participants aged ≥5 years (as VA was not determined for children aged 0-4 years) VA data missing for one person;

* Estimates of prevalence of severity of hearing impairment are restricted to those aged >3 years (as severity not determined for children aged 0-3 years). NB data also missing for 2 adults

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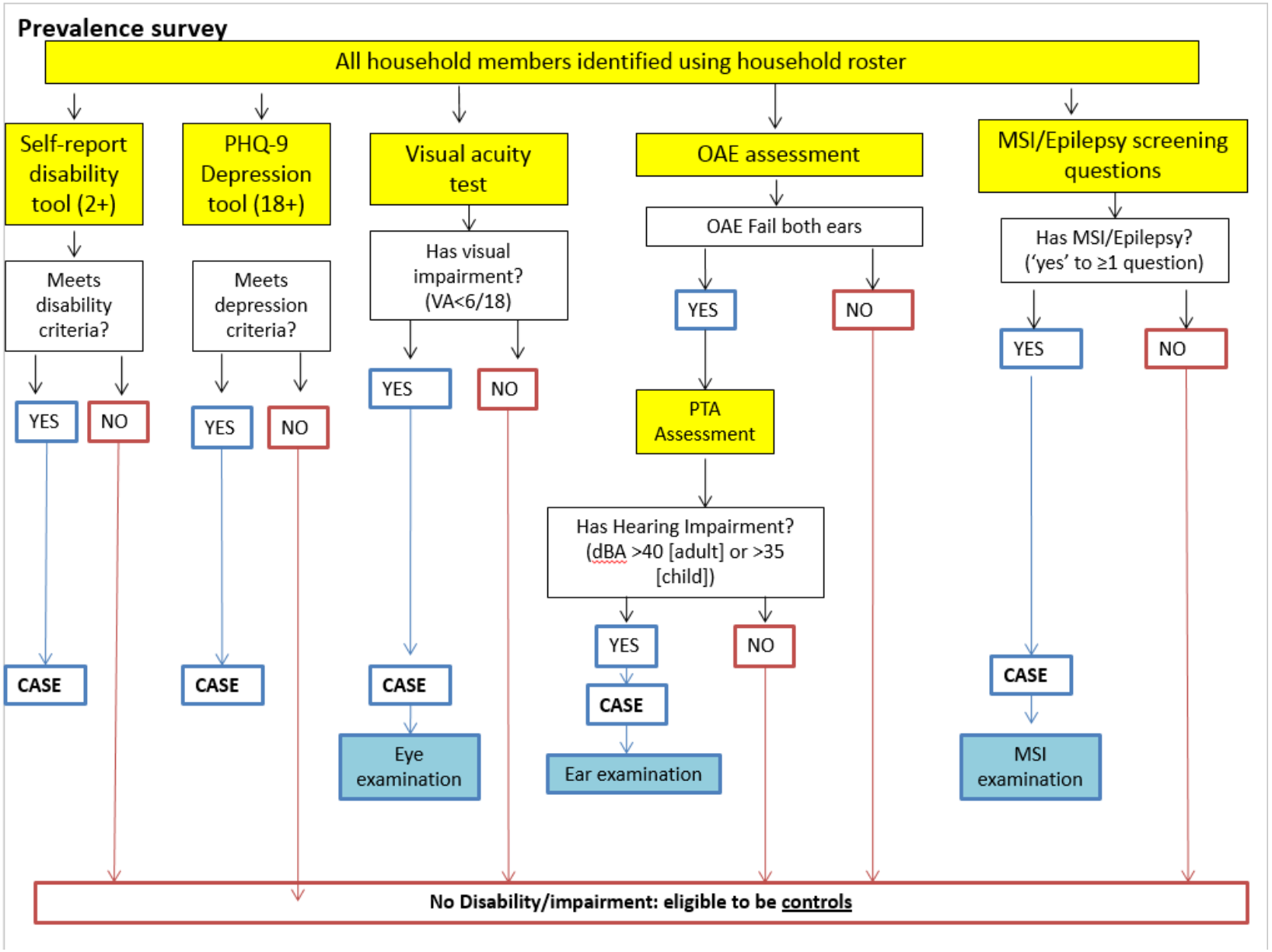
APPENDIX 1: SCREENING PROTOCOL



APPENDIX 2: Screening Questionnaire

INDIA DISABILITY STUDY 2014 - Screening and Examination Questionnaire

1. Interviewer No: ☐☐☐ 2. Date (Day/Month/Year): __ __/__ __/__ __

3. Cluster No: ☐☐ 4. House No: ☐☐

5. Subject Name: _____ 6. Subject ID No: ☐☐☐

7. Gender Male: O (1) Female: O (2) 8. Age (years): ☐☐ 9. Age (in months if <1 year): ☐☐

10. Religion Hindu O (1) Muslim O (2) Christian O (3) Sikh O (4) Other O (5) Specify: _____

11. Caste OC O (1) BC O (2) SC O (3) SC O (4) ST O (5) FC O (6) Other O (7) Specify: _____

12. Screening Summary

	12.1 Screen Case? 0 = NO 1= YES		12.2 Exam Completed? 1 = YES 2 = Unable 3 = Refused			12.3 Follow up exam needed? 0 = NO 1 = YES		12.4 Referral Given? 0 = NO 1 = YES	
A. WG Disability	O (0)	O (1)							
B. PHQ9	O (0)	O (1)						O (0)	O (1)
C. MSI Impairment	O (0)	O (1)	O (1)	O (2)	O (3)			O (0)	O (1)
D. Visual Impairment	O (0)	O (1)	O (1)	O (2)	O (3)	O (0)	O (1)	O (0)	O (1)
E. Hearing (OAE)	O (0)	O (1)				O (0)	O (1)	O (0)	O (1)
F. Hearing (PTA)	O (0)	O (1)	O (1)	O (2)	O (3)	O (0)	O (1)	O (0)	O (1)

TO BE FILLED IN BY FIELD TEAM MEMBER RESPONSIBLE FOR CHECKING QUESTIONNAIRES FOR COMPLETION	CONFIRMED
REMARKS: _____ Interviewer #	Case O (1) Control O (2) Not eligible for Case/Control O (3)

FOR MATCHED CASES AND CONTROLS:	
Household Head (Y/N)	☐
Previous HH member Interviewed (Y/N)	☐
If yes, ID Number of HH member	☐☐
If Proxy, Proxy ID	☐☐
Interviewer: Mark when Complete	☐

TO BE FILLED IN BY DATA ENTRY CLERK		
	Entry 1	Entry 2
INITIALS:		
DATE OF ENTRY:		
REMARKS:		

1

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Int. ID No. ☐☐☐

A. Washington Group Questions for all participants AGED 2 to 17

I am now going to ask you some questions about certain everyday activities, and whether you have any difficulties in doing them. Please tell me if you do not understand question, and I will repeat it

Note to Interviewer: If respondent is aged 8-17 and being interviewed directly, replace "does [name]" with "do you" in questions. Read all response options in full for each question asked

0. Who is responding? **Child directly O (1)** **Proxy response for child O (0)**

All children aged 2-17 years

1a) Does [name] wear glasses or contact lenses Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
[if child wears glasses] 1b) Does [name] have difficulty seeing, when wearing his/her glassses?	O (1)	O (2)	O (3)	O (4)	O (5)
[if child does NOT wear glasses] 1c) Does [name] have difficulty seeing?	O (1)	O (2)	O (3)	O (4)	O (5)

2a) Does [name] use a hearing aid? Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
[if child uses a hearing aid] 2b) Does [name] have difficulty hearing, when using his/her hearing aid(s)?	O (1)	O (2)	O (3)	O (4)	O (5)
[if child does NOT use a hearing aid] 2c) Does [name] have difficulty hearing?	O (1)	O (2)	O (3)	O (4)	O (5)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
Children aged 2-17 years 3) Compared with children of the same age, does [name] have difficulty walking?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 5- 17 years 4) Compared with children of the same age, does [name] have difficulty with self-care such as feeding or dressing him/herself?	O (1)	O (2)	O (3)	O (4)	O (5)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
Children aged 2 -4 years 5a) Does [name] have difficulty understanding you?	O (1)	O (2)	O (3)	O (4)	O (5)
6a) Do you have difficulty understanding what your child wants?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 5-17 years # 5b) Compared with children of the same age and using [his/her] usual language, does [name] have difficulty understanding other people?	O (1)	O (2)	O (3)	O (4)	O (5)
6b)Compared with children of the same age and using [his/her] usual language, does [name] have difficulty being understood by other people?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 2-3 years 7a) Compared with children of the same age, does [name] have difficulty learning the names of common objects?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 3-17 years 7b) Compared with children of the same age, does [name] have difficulty learning to do new things?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 5-17 years 8) Compared with children of the same age, does [name] have difficulty remembering things that they have learned?	O (1)	O (2)	O (3)	O (4)	O (5)

2

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Int. ID No. ☐☐☐

	The same or Less	More	A lot more	Dont Know
Children aged 5-17 years 9) Compared with children of the same age, how much does [he /she] worry or feel sad?	O (1)	O (2)	O (3)	O (4)
Children aged 2-4 years 10a) Compared with children of the same age, how much does [name] kick, bite or hit other children or adults?	O (1)	O (2)	O (3)	O (4)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
Children aged 5-17 years 10b) Compared with children of the same age, how much difficulty does [name] have controlling [his/her] behaviour?	O (1)	O (2)	O (3)	O (4)	O (5)
11) Compared with children of the same age, does [name] have difficulty completing a task?	O (1)	O (2)	O (3)	O (4)	O (5)
12) Compared with children of the same age, does [name] have difficulty accepting change to plans or routine?	O (1)	O (2)	O (3)	O (4)	O (5)
13) Does [name] have difficulty getting along with children of [his/her] age?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 2-5 years 14 a1) Compared with children of the same age, does [name] have difficulty playing with toys or household objects?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 2-12 years 14a2) Compared with children of the same age, does [name] have difficulty playing with other children?	O (1)	O (2)	O (3)	O (4)	O (5)
Children aged 13-17 years 14b) Compared with children of the same age, does [name] have difficulty doing things with other children? (Include things that children usually do together.)	O (1)	O (2)	O (3)	O (4)	O (5)

15. Do you consider yourself [your child] to have a disability? O (1) Yes
O (0) No

Child SCREENS POSITIVE IF:
ANY QUESTION 1 to 8 SCORES "A lot More", "A lot of Difficulty" or "Cannot do at all"

Screen case: O (1)
Not Screen case: O (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

To Parent (FOR CASES): Based on your/ your child's responses, it seems that your child may experience difficulties in doing certain things compared to other children his/her age, and we would like to ask some more questions about this.

3

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Interviewer ID No. ☐☐☐

A. Washington Group Questions for all participants 18+

I am now going to ask you some questions about certain everyday activities, and whether you have any difficulties in doing them. Please tell me if you do not understand question, and I will repeat it

Note to Interviewer: Read all response options in full for each question asked

1a) Do you wear glasses or contact lenses Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
[If respondent wears glasses/contact lenses] 1b) Do you have difficulty seeing, even when wearing your glassses/contact lenses?	O (1)	O (2)	O (3)	O (4)	O (5)
[If respondent does NOT wear glasses/contact lenses] 1c) Do you have difficulty seeing?	O (1)	O (2)	O (3)	O (4)	O (5)

2a) Do you use a hearing aid? Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
[If respondent uses a hearing aid] 2b) Do you have difficulty hearing, even when using your hearing aid(s)?	O (1)	O (2)	O (3)	O (4)	O (5)
[If respondent does NOT use a hearing aid] 2c) Do you have difficulty hearing?	O (1)	O (2)	O (3)	O (4)	O (5)

3a) Do you use any equipment or receive help for getting around? Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
[If respondent uses equipment or receives help to get around] 3b) Do you have difficulty walking or climbing steps, even when using your equipment or with help?	O (1)	O (2)	O (3)	O (4)	O (5)
[If respondent does NOT use equipment or receive help to get around] 3c) Do you have difficulty walking or climbing steps?	O (1)	O (2)	O (3)	O (4)	O (5)

4a) Do you use sign language? Yes O (1) No O (0)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
4b) Using your usual language, do you have difficulty communicating, for example understanding or being understood?	O (1)	O (2)	O (3)	O (4)	O (5)

	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Don't know
5) Do you have difficulty remembering or concentrating?	O (1)	O (2)	O (3)	O (4)	O (5)
6) Do you have difficulty with self care, such as washing all over or dressing?	O (1)	O (2)	O (3)	O (4)	O (5)
7) Do you have difficulty raising a 2 litre bottle of water or soda from waist to eye level?	O (1)	O (2)	O (3)	O (4)	O (5)
8) Do you have difficulty using your hands and fingers, such as picking up small objects, for example a button or pencil, or opening or closing containers or bottles	O (1)	O (2)	O (3)	O (4)	O (5)

	Daily	Weekly	Monthly	A few times a year	Never	Dont Know
9a) How often do you feel worried, nervous or anxious?	O (1)	O (2)	O (3)	O (4)	O (5)	O (6)

→ **If NEVER or DONT KNOW to 9a] Go to Q10**

4

Cluster no: ☐☐ Household no: ☐☐☐ Subject ID no: ☐☐☐ Interviewer ID No. ☐☐☐

9b) Do you take medication for these feelings? Yes O (1) No O (0)

	A little	A lot	Somewhere between a little and a lot	Dont Know
9c) Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	O (1)	O (2)	O (3)	O (4)

	Daily	Weekly	Monthly	A few times a year	Never	Dont Know
10 a) How often do you feel depressed? Would you say	O (1)	O (2)	O (3)	O (4)	O (5)	O (6)

→ **If NEVER or DONT KNOW to 10a) Go to Q 11**

10b) Do you take medication for depression? Yes O (1) No O (0)

	A little	A lot	Somewhere between a little and a lot	Dont Know
10c) Thinking about the last time you felt depressed, how depressed did you feel?	O (1)	O (2)	O (3)	O (4)

	Never	Some Days	Most Days	Every Day	Dont Know
11a) In the past three months, how often did you have pain?	O (1)	O (2)	O (3)	O (4)	O (5)

→ **If NEVER or DONT KNOW to 11a) go to Q12**

	A little	A lot	Somewhere between a little and a lot	Dont Know
11b) Thinking about the last time you felt pain, how much pain did you have?	O (1)	O (2)	O (3)	O (4)

	Never	Some Days	Most Days	Every Day	Dont Know
12a) In the past three months, how often did you feel very tired or exhausted?	O (1)	O (2)	O (3)	O (4)	O (5)

→ **If NEVER to 12a) go to END OF SECTION**

	Some of the day	Most of the day	All of the day	Dont Know
12b) Thinking about the last time you felt very tired or exhausted, how long did it last?	O (1)	O (2)	O (3)	O (4)

	A little	A lot	Somewhere between a little and a lot	Dont Know
12c) Thinking about the last time you felt this way, how would you describe the level of tiredness?	O (1)	O (2)	O (3)	O (4)

Participant SCREENS POSITIVE If:Any Question 1 to 8 scores "A lot", "A lot of Difficulty" or "Cannot do at all"

13. Do you consider yourself to have a disability? O (1) Yes O (0) No

Screen case: O (1)
Not Screen case: O (0)

To Participant: Based on your responses, it seems that you may experience difficulties in doing certain things compared to other people, and we would like to ask some more questions about this.

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐ Interviewer ID No. ☐☐

B. PHQ-9 Questions for all participants 18+

I am now going to ask you a few questions about how you have been feeling recently. Please tell me if you do not understand a question, and I will repeat it

Over the last two weeks, how often have you been bothered by any of the following problems?

	Not at all	Several Days	More than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	O (0)	O (1)	O (2)	O (3)
2. Feeling down, depressed, or hopeless	O (0)	O (1)	O (2)	O (3)
3. Feeling tired or having little energy	O (0)	O (1)	O (2)	O (3)

→ **If no responses in SHADED AREA [answer of (2) or (3)] go to NEXT SECTION**

4. Trouble falling/staying asleep, sleeping too much	O (0)	O (1)	O (2)	O (3)
5. Poor appetite or overeating	O (0)	O (1)	O (2)	O (3)
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	O (0)	O (1)	O (2)	O (3)
7.Trouble concentrating on things, such as reading the newspaper or watching television	O (0)	O (1)	O (2)	O (3)
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	O (0)	O (1)	O (2)	O (3)
9.Thoughts that you would be better off dead or of hurting yourself in some way	O (0)	O (1)	O (2)	O (3)

Column Totals: _____ + _____ + _____

Total Score (Add Totals together): _____

Participant SCREENS POSITIVE if: Total score 20 or ABOVE and includes at least one answer in the shaded area

Screen case: O (1)
Not Screen case: O (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

To Participant: Based on your responses, it seems that you may experience difficulties in doing certain things compared to other people, and we would like to ask some more questions about this.

C. RAPID ASSESSMENT OF MUSCULOSKELETAL IMPAIRMENT

A. GENERAL INFORMATION

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

Examination status: Examined: O (1)
Unable to examine: O (2) Reason: _____
Refused: O (3)

B. SCREEN FOR MUSCULOSKELETAL IMPAIRMENT

I am going to ask you now a few questions about your physical health and abilities.

1. Who is responding?
Screen by eligible person: O (1)
Screen by proxy: O (0)

2. *Use this prefix for 5 and under (by proxy): Compared to other children*

	Yes	No
1. Is any part of your body missing or misshapen?:	O (1)	O (0)
2. Do you have any difficulty using your arms?:	O (1)	O (0)
3. Do you have any difficulty using your legs?:	O (1)	O (0)
4. Do you have any difficulty using any other part of your body?:	O (1)	O (0)
5. Do you use a mobility aid or prosthesis?:	O (1)	O (0)
6. Do you have convulsions, involuntary movement, rigidity or loss of consciousness?:	O (1)	O (0)
7. Do you have any difficulty using your back?	O (1)	O (0)

3. Duration

	Yes	No
1. Has it lasted>1m?	O (1)	O (0)
2. Is it permanent?	O (1)	O (0)

Examine Participant if: Answer to at least one Q 1-6 is Yes and Answer to at least one "Duration" question is Yes

MSI Exam Needed Yes O (1) No O (0)

C. OBSERVATION OF ACTIVITIES

		CAN DO	CANT DO
I. Position	Squat/sit bending knees:	O (1)	O (0)
	Stand up straight on natural legs:	O (1)	O (0)
	Hold arms straight above head, fingers straight:	O (1)	O (0)
II. Mobility	Walk along the 11 metre rope:	O (1)	O (0)
	Do it in less than 10 secs:	O (1)	O (0)
	Do it without limping:	O (1)	O (0)
III. Right hand function	Touch Nose:	O (1)	O (0)
	Pick up coin and put in cup:	O (1)	O (0)
	Tip coin into bowl:	O (1)	O (0)
IV. Left hand function	Touch Nose:	O (1)	O (0)
	Pick up coin and put in cup:	O (1)	O (0)
	Tip coin into bowl:	O (1)	O (0)

D. SEIZURE HISTORY

1 Have you ever had a seizure?
No history of seizure: O (0) → Go to section E
History of seizure: O (1) → Go to Q2

2 Have you had three or more seizures in the past year?
3 or more seizures No O (0)
Yes O (1)

3 Number of episodes in last year:
0: O (1)
1-2: O (2)
3-10: O (3)
>10: O (4)

4 Type of seizure (tick one only)
Absences: O (1)
Convulsions: O (2)

E. DURATION AND CONSANGUINITY

1 Age at impairment:
Since birth: O (1)
after birth-1 year: O (2)
1-5 years O (3)
6-15 years: O (4)
16-39 years: O (5)
>40 years: O (6)
Not applicable (No impairment:) O (7)

	No	Yes
2 Consanguinity:	O (0)	O (1)

F. AETIOLOGY

Tick one only for each impairment

	Impairment no:	1	2
	Family history:	O	O (1)
	Congenital but no family history:	O	O (2)
	Perinatal hypoxia:	O	O (3)
Trauma	RTA:	O	O (4)
	Civil violence:	O	O (5)
	Domestic violence:	O	O (6)
	Deliberate self harm:	O	O (7)
	Other inc accidents:	O	O (8)
	Specify.....		
	Developmental / Nutritional:	O	O (9)
	Infection:	O	O (10)
	Neoplasm:	O	O (11)
	Iatrogenic:	O	O (12)
	Traditional	O	O (13)
	Unknown:	O	O (14)
	Other:	O	O (15)
	Specify.....		
	Not applicable (No impairment:)	O	O (16)

G. STRUCTURE AND FUNCTION

Region	Structure affected Yes	Structure affected No	Laterality Left = 1 Right = 2 Both = 3	Nature of change (see codes below)	Magnitude (see codes below)
1. Head and Neck	O (1)	O (0)			
2. Shoulder region	O (1)	O (0)			
3. Upper arm	O (1)	O (0)			
4. Elbow Joint	O (1)	O (0)			
5. Forearm	O (1)	O (0)			
6. Wrist Joint	O (1)	O (0)			
7. Hand	O (1)	O (0)			
8. Hand/Finger Joints	O (1)	O (0)			
9. Whole arm	O (1)	O (0)			
10. Pelvis	O (1)	O (0)			
11. Hip joint	O (1)	O (0)			
12. Thigh	O (1)	O (0)			
13. Knee Joint	O (1)	O (0)			
14. Lower leg	O (1)	O (0)			
15. Ankle Joint	O (1)	O (0)			
16. Foot	O (1)	O (0)			
17. Foot/Toe Joints	O (1)	O (0)			
18. Whole Leg	O (1)	O (0)			
19. Trunk	O (1)	O (0)			
20. C-spine	O (1)	O (0)			
21. T-spine	O (1)	O (0)			
22. L-spine	O (1)	O (0)			
23. Whole body	O (1)	O (0)			

Nature of Change Codes: No change in structure = 0; Total absence = 1; Partial absence = 2; Additional Part = 3; Aberrant dimensions = 4; Discontinuity = 5; Deviating Position = 6; Qualitative changes = 7; Not Specified = 8; Not applicable = 9

Magnitude of Function: No impairment = 0; Mild Impairment = 1; Moderate Impairment = 2; Severe Impairment = 3; Complete Impairment = 4

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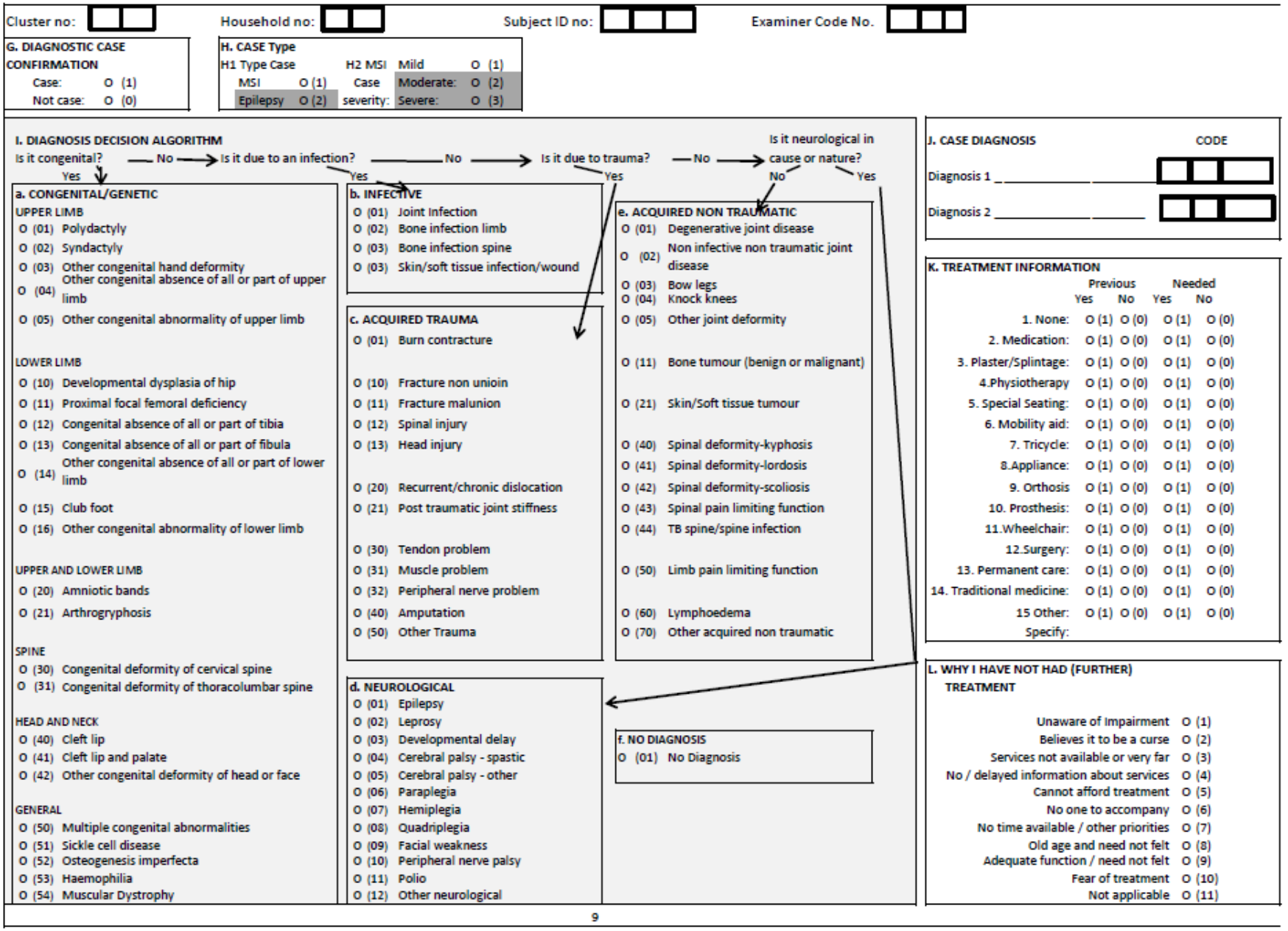

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

G. DIAGNOSTIC CASE CONFIRMATION

Case: O (1)
Not case: O (0)

H. CASE Type

H1 Type Case
MSI O (1)
Epilepsy O (2)

H2 MSI Case severity:
Mild O (1)
Moderate: O (2)
Severe: O (3)

I. DIAGNOSIS DECISION ALGORITHM

Is it congenital? Yes → a. CONGENITAL/GENETIC
No → Is it due to an infection? Yes → b. INFECTIVE
No → Is it due to trauma? Yes → c. ACQUIRED TRAUMA
No → Is it neurological in cause or nature? Yes → d. NEUROLOGICAL
No → e. ACQUIRED NON TRAUMATIC

a. CONGENITAL/GENETIC

UPPER LIMB
O (01) Polydactyly
O (02) Syndactyly
O (03) Other congenital hand deformity
O (04) Other congenital absence of all or part of upper limb
O (05) Other congenital abnormality of upper limb

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

UPPER AND LOWER LIMB
O (20) Amniotic bands
O (21) Arthrogryphosis

SPINE
O (30) Congenital deformity of cervical spine
O (31) Congenital deformity of thoracolumbar spine

HEAD AND NECK
O (40) Cleft lip
O (41) Cleft lip and palate
O (42) Other congenital deformity of head or face

GENERAL
O (50) Multiple congenital abnormalities
O (51) Sickle cell disease
O (52) Osteogenesis imperfecta
O (53) Haemophilia
O (54) Muscular Dystrophy

b. INFECTIVE

O (01) Joint Infection
O (02) Bone infection limb
O (03) Bone infection spine
O (03) Skin/soft tissue infection/wound

c. ACQUIRED TRAUMA

O (01) Burn contracture
O (10) Fracture non unioin
O (11) Fracture malunion
O (12) Spinal injury
O (13) Head injury
O (20) Recurrent/chronic dislocation
O (21) Post traumatic joint stiffness
O (30) Tendon problem
O (31) Muscle problem
O (32) Peripheral nerve problem
O (40) Amputation
O (50) Other Trauma

d. NEUROLOGICAL

O (01) Epilepsy
O (02) Leprosy
O (03) Developmental delay
O (04) Cerebral palsy - spastic
O (05) Cerebral palsy - other
O (06) Paraplegia
O (07) Hemiplegia
O (08) Quadriplegia
O (09) Facial weakness
O (10) Peripheral nerve palsy
O (11) Polio
O (12) Other neurological

e. ACQUIRED NON TRAUMATIC

O (01) Degenerative joint disease
O (02) Non infective non traumatic joint disease
O (03) Bow legs
O (04) Knock knees
O (05) Other joint deformity
O (11) Bone tumour (benign or malignant)
O (21) Skin/Soft tissue tumour
O (40) Spinal deformity-kyphosis
O (41) Spinal deformity-lordosis
O (42) Spinal deformity-scoliosis
O (43) Spinal pain limiting function
O (44) TB spine/spine infection
O (50) Limb pain limiting function
O (60) Lymphoedema
O (70) Other acquired non traumatic

f. NO DIAGNOSIS

O (01) No Diagnosis

J. CASE DIAGNOSIS CODE

Diagnosis 1 _____ ☐☐☐
Diagnosis 2 _____ ☐☐☐

K. TREATMENT INFORMATION

	Previous Yes	Previous No	Needed Yes	Needed No
1. None:	O (1)	O (0)	O (1)	O (0)
2. Medication:	O (1)	O (0)	O (1)	O (0)
3. Plaster/Splintage:	O (1)	O (0)	O (1)	O (0)
4.Physiotherapy	O (1)	O (0)	O (1)	O (0)
5. Special Seating:	O (1)	O (0)	O (1)	O (0)
6. Mobility aid:	O (1)	O (0)	O (1)	O (0)
7. Tricycle:	O (1)	O (0)	O (1)	O (0)
8.Appliance:	O (1)	O (0)	O (1)	O (0)
9. Orthosis	O (1)	O (0)	O (1)	O (0)
10. Prosthesis:	O (1)	O (0)	O (1)	O (0)
11.Wheelchair:	O (1)	O (0)	O (1)	O (0)
12.Surgery:	O (1)	O (0)	O (1)	O (0)
13. Permanent care:	O (1)	O (0)	O (1)	O (0)
14. Traditional medicine:	O (1)	O (0)	O (1)	O (0)
15 Other:	O (1)	O (0)	O (1)	O (0)
Specify:				

L. WHY I HAVE NOT HAD (FURTHER) TREATMENT

Unaware of Impairment O (1)
Believes it to be a curse O (2)
Services not available or very far O (3)
No / delayed information about services O (4)
Cannot afford treatment O (5)
No one to accompany O (6)
No time available / other priorities O (7)
Old age and need not felt O (8)
Adequate function / need not felt O (9)
Fear of treatment O (10)
Not applicable O (11)

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Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

D. VISUAL IMPAIRMENT

A. GENERAL INFORMATION

Examination status: Examined: O (1)
Unable to examine: O (2) Reason:
Refused: O (3)

Screen Case: O (1)
Not Screen case: O (0)

Always ask: "Did you ever have any problems with your eyes?"

B. VISION SCREEN

Using distance glasses: Yes O (1) No O (0)
Using reading glasses: Yes O (1) No O (0)

i)AGE 5+ YEARS

Presenting	Right eye	Left eye
Can see 6/12	O (1)	O (1)
Cannot see 6/12 but can see 6/18	O (2)	O (2)
Cannot see 6/18 but can see 6/60	O (3)	O (3)
Cannot see 6/60 but can see 3/60	O (4)	O (4)
Cannot see 3/60 but can see 1/60	O (5)	O (5)
Light perception (PL+)	O (6)	O (6)
No light perception (PL-)	O (7)	O (7)

CASE

With Pinhole

	Right eye	Left eye
Can see 6/12	O (1)	O (1)
Cannot see 6/12 but can see 6/18	O (2)	O (2)
Cannot see 6/18 but can see 6/60	O (3)	O (3)
Cannot see 6/60 but can see 3/60	O (4)	O (4)
Cannot see 3/60 but can see 1/60	O (5)	O (5)
Light perception (PL+)	O (6)	O (6)
No light perception (PL-)	O (7)	O (7)

ii)AGE 0-2 YEARS

Can the child look at and follow a moving object? Yes: O (1) No: O (0)

iii)AGE 3-4 YEARS

Can child count/copy fingers from 6 meters with both eyes open? Yes: O (1) No: O (0)

E. WHY CATARACT OPERATION WAS NOT DONE

(Mark up to 2 responses, if VA<6/18 not improving with pinhole, with visually impairing lens opacity in one or both eyes)

- Need not felt O (1)
- Fear of surgery or poor result O (2)
- Cannot afford operation O (3)
- Treatment denied by provider O (4)
- Unaware treatment is possible O (5)
- No one to accompany O (6)
- No time available / other priorities O (7)
- Told to wait for cataract to mature O (8)

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C. LENS EXAMINATION

	Right eye	Left eye
Normal lens / minimal lens opacity:	O (1)	O (1)
Obvious lens opacity:	O (2)	O (2)
Lens absent (aphakia):	O (3)	O (3)
Pseudophakia without P 70	O (4)	O (4)
Pseudophakia with PCO:	O (5)	O (5)
No view of lens:	O (6)	O (6)

D. MAIN CAUSE OF PRESENTING VA<6/12

(Mark only one cause for each eye)

	Right eye	Left eye	Principal cause in person
Refractive error:	O (1)	O (1)	O (1)
Cataract, untreated	O (2)	O (2)	O (2)
Aphakia, uncorrected:	O (3)	O (3)	O (3)
Surgical complications:	O (4)	O (4)	O (4)
Trachoma:	O (5)	O (5)	O (5)
Phthisis/disorganised/removed:	O (6)	O (6)	O (6)
Other corneal scar/opacity:	O (7)	O (7)	O (7)
Other/not known	O (8)	O (8)	O (8)
Not examined (can see 6/12)	O (9)	O (9)	O (9)

F. DETAILS ABOUT CATARACT OPERATION

	Right eye	Left eye
Age at operation (years)	☐☐	☐☐
Place of operation		
Government hospital	O (1)	O (1)
Voluntary / charitable hospital	O (2)	O (2)
Private hospital	O (3)	O (3)
Eye camp / improvised setting	O (4)	O (4)
Traditional setting	O (5)	O (5)
Type of surgery		
Non IOL	O (1)	O (1)
IOL implant	O (2)	O (2)
Couching	O (3)	O (3)
Cost of surgery		
Totally free	O (1)	O (1)
Partially free	O (2)	O (2)
Fully paid	O (3)	O (3)
Cause of VA<6/18 after cataract surgery		
Ocular comorbidity (Selection)	O (1)	O (1)
Operative complications (Surgery)	O (2)	O (2)
Refractive error (Spectacles)	O (3)	O (3)
Longterm complications (Sequelae)	O (4)	O (4)
Does not apply - can see 6/18	O (5)	O (5)
Are you satisfied with results of cataract surgery?		
Very satisfied	O (1)	O (1)
Partially satisfied	O (2)	O (2)
Indifferent	O (3)	O (3)
Partially dissatisfied	O (4)	O (4)
Very dissatisfied	O (5)	O (5)

E. OAE SCREEN FOR HEARING IMPAIRMENT

Cluster no ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

1. OAE Equipt No. ☐☐

2

RIGHT EAR	Pass	Fail	Not done - discharging ear	Not done - other
	O (1)	O (2)	O (3)	O (4)

LEFT EAR	Pass	Fail	Not done - discharging ear	Not done - other
	O (1)	O (2)	O (3)	O (4)

3 State reason if "not done - other": _____

Pure Tone Audiometry (PTA) needed if Participant FAILS OAE in BOTH EARS or if OAE can not be done/read for any reason

Pure Tone Audiometry Test Needed Yes O (1) No (0)

If "NO", mark "Not Screen Case" below and COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

F. PTA FOR HEARING IMPAIRMENT IF BOTH EARS FAIL OAE

II. AUDIOMETRY **If aged 4+ and OAE fails in BOTH ears or can not be done**

1. Ambient Noise ☐☐☐ dBA 2. PTA Equipment No. ☐☐

2. Hearing Thresholds

		Right (dBHL)	Left (dBHL)
a.	1 KHz	☐☐	☐☐
b.	2 KHz	☐☐	☐☐
c.	4 KHz	☐☐	☐☐
d.	0.5 KHz	☐☐	☐☐
e.	1 KHz	☐☐	☐☐
f. Average score a-d		☐☐	☐☐

Note: If 1KHz (e.) score not within +/- 5dbHL of 1KHz (a.) score repeat PTA screen

Partipant SCREENS POSITIVE if Average score (f) is >35dBa for 0-17 year olds or >40dBa for 18+ in BOTH ears

Screen case: O (1)
Not Screen case: O (0)

COMPLETE FRONT PAGE BEFORE STARTING NEXT SECTION

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G. WHO/PBD Ear and Hearing Disorders Examination Form

A. GENERAL INFORMATION

Cluster no: ☐☐ Household no: ☐☐ Subject ID no: ☐☐☐ Examiner Code No. ☐☐☐

B. BASIC EAR ASSESSMENT FOR HEARING IMPAIRMENT CASES ONLY

	Right			Left		
	No	Yes	Not Asked	No	Yes	Not Asked
I. Ear Pain	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)

	Right			Left		
	N	M	N/E	N	M	N/E
II. Auricle	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)

N = Normal; M= Malformation; N/E = Not Examined

	Right			Left		
III. External Canal	N	Y	N/E	N	Y	N/E
1. Normal	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
2. Inflammation	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
3. Wax	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
Removed?	O (0)	O (1)		O (0)	O (1)	
4. Foreign Body	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
Removed?	O (0)	O (1)		O (0)	O (1)	
5. Otorrhoea	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)
Removed?	O (0)	O (1)		O (0)	O (1)	
6. Fungi	O (0)	O (1)	O (2)	O (0)	O (1)	O (2)

N= No; Y= Yes; N/E = Not Examined

	Right				Left			
IV. Ear Drum	N	Y	N/E	U	N	Y	N/E	U
1. Perforation	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
2. Dullness or Retraction	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
3. Red and Bulging	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
4. Normal	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)

N= No; Y= Yes; N/E = Not Examined; U= Unsure

	Right				Left			
V. Middle Ear	N	Y	N/E	U	N	Y	N/E	U
1. Normal	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
2. Otorrhoea	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)
VI. Others	O (0)	O (1)	O (2)	O (3)	O (0)	O (1)	O (2)	O (3)

1. If Yes, Specify _____

VII. Additional Information

1. How Long has the subject had difficulty hearing?

Since Infancy/childhood (0-4y) O (1)
Somce adulthood (15-59y) O (2)
Since old age (60y+) O (3)
Uncertain O (4)
No Difficulty O (5)
Not Asked O (6)

2. Does any relative of the subject have difficulty hearing?

No O (0)
Yes O (1) → 3. If yes, specify: Brother or Sister O (1); Child of Subject O (2); Parent of Subject O (3)
Uncertain O (3)
Not Asked O (4)

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D. CAUSE OF EAR DISEASE AND/OR HEARING IMPAIRMENT

Please tick all that apply

	Right ear	Left ear
Normal ear **AND** normal hearing	O (1)	O (1)
I. Ear Disease		
1. Wax	O (2)	O (2)
2. Foreign Body	O (3)	O (3)
3. Otitis Externa...	O (4)	O (4)
4. Acute Otitis Media	O (5)	O (5)
5. Chronic Suppurative Otitis Media	O (6)	O (6)
6. Serous Otitis media (with effusion)	O (7)	O (7)
7. Dry perforation of Tympanic Membrane	O (8)	O (8)
II. Infectious Diseases	O (9)	O (9)
Specify _____		
III. Genetic Conditions	O (10)	O (10)
Specify _____		
IV. Non-Infectious Conditions	O (11)	O (11)
Specify _____		
V. Underermined Cause	O (12)	O (12)
Specify _____		
VI. Other	O (13)	O (13)
Specify _____		

E. ACTION NEEDED

I. No Action Needed O (1)

II. Action Needed	N	Y	U
1. Medication	O (0)	O (1)	O (2)
2. Hearing Aid	O (0)	O (1)	O (2)
3. Language/Speech Rehabilitation	O (0)	O (1)	O (2)
4. Special Needs Education	O (0)	O (1)	O (2)
5. Vocational Training	O (0)	O (1)	O (2)
6. Surgery Referral	O (0)	O (1)	O (2)
Urgent	O (0)	O (1)	O (2)
Non Urgent	O (0)	O (1)	O (2)

N= No; Y= Yes; U=Unsure

	N	Y	U
7. Others	O (0)	O (1)	O (3)

*Specify*_____

III. Any Additional Examiner Remarks:
_____
_____
_____
_____

APPENDIX 3: CLINICAL IMPAIRMENT SEVERITY DEFINITIONS

Table xx: Clinical impairment severity definitions

	Measurement	Severity	Threshold
Vision	Visual Acuity – presenting vision in better eye	No Impairment	VA> 6/18
		Early*	VA<6/12 but >6/18
		Moderate	VA <6/18 but >6/60
		Severe	VA <6/60 but >3/60
		Profound (blind)	VA <3/60
Hearing	Level of hearing loss in better ear	No Impairment	<25 dBA (adults) and <35 dBA (children)
		Mild*	25-40 dBA (adults)
		Moderate	41-60db (adults), 35-60db (children)
		Severe	61-80db
		Profound (deaf)	>80dba
MSI	Overall functional performance of musculoskeletal system based on observation and examination	No Impairment	No presence of musculoskeletal structural impairment that affects the structures ability to function at all
		Mild*	Structure impairment with mild effect on the musculoskeletal system's ability to function as a whole 5-24%
		Moderate	Structure impairment with moderate effect on the musculoskeletal system's ability to function as a whole 25-49%
		Severe	Structure impairment with severe effect on the musculoskeletal system's ability to function as a whole 50-100%

*Early/ Mild impairments not included in estimates of disability/overall estimates of prevalence of clinical impairments