International Centre for Evidence in Disability

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Building the Evidence Base in Disability
Research Summary

Study Background

- Few robust quantitative data on the magnitude and impact of disability on people's lives are available globally
- Amongst the limited evidence base that exists, different methodologies used in defining disability make comparison between countries and over time extremely difficult
- Collection of comparable disability data advocated by WHO World Report on Disability and ongoing Post 2015 debates

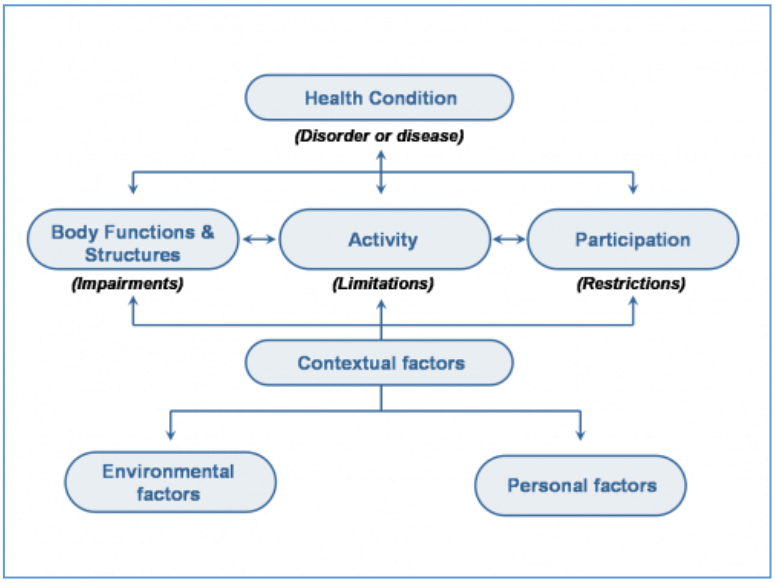

Fig 1: ICF Framework of disability

Defining Disability

The International Classification of Functioning, Disability of Health Disability (ICF) Model (Fig 1) defines disability as the interaction between:

1. Health conditions and/or impairments in body function and structure
2. Activity limitations
3. Participation restrictions

The relationship between these components is strongly mediated by environmental, personal and contextual factors.

Previous studies that have measured disability have used tools that focus on one component or another within the ICF, but no previous study has compared how the different approaches to measuring disability inter-relate, and how disability is captured comprehensively

Photo: A young girl waits for screening in India

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Study Aim:

To develop a comprehensive population-based survey methodology that is compatible with the ICF, and to explore the inter-relationship between the components of this framework.

Study Objectives:

1. Identify and review existing tools for self-reported disability measurement in population based surveys
2. Develop a population-based survey methodology to assess prevalence of impairment and self-reported disability and to undertake this survey in two countries.
3. Explore the relationship between objectively-measured impairment and self-reported disability within the context of the ICF
4. Assess the impact of disability on participation, access to health, education, employment and livelihood in two countries
5. Identify socio-demographic, economic, environmental and clinical predictors of access to health, education and employment among people with disabilities

Study Design:

1. Population-based survey of disability (n=4080) in:

1) Mahbubnagar District, Telangana State (India)
2) Fundong District, North West Cameroon

   a. Self-reported activity limitations
   b. Clinical screening for visual impairment, hearing impairment, musculoskeletal impairment 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, and participation.
   b. Availability of rehabilitation, inclusive education and assistive devices

3. Qualitative study: 30 participants identified with disabilities from the population-based sample and the nested case control, plus 14 key informants, interviewed using a semi-structured questionnaire

Definition of disability used in the study:

Screening criteria used to identify persons with disabilities were based on international recommendations for "significant" activity limitations and "moderate/severe" clinical impairments or disabling health conditions:

- Self-reported Activity Limitations: reporting "a lot of difficulty" or "cannot do" in any basic activity domain
- Vision Impairment: Presenting vision in better eye of <6/18
- Hearing Impairment: Presenting hearing loss in better ear of >40 dBA (adults) or >35dBA (children)
- Musculoskeletal Impairment (MSI): Structure impairment with moderate effect on the musculoskeletal system's ability to function as a whole 25-49%
- Epilepsy: 3 or more tonic clonic seizures previously
- Depression: score of 20 or above on PHQ-9 Questionnaire (aged 18+)

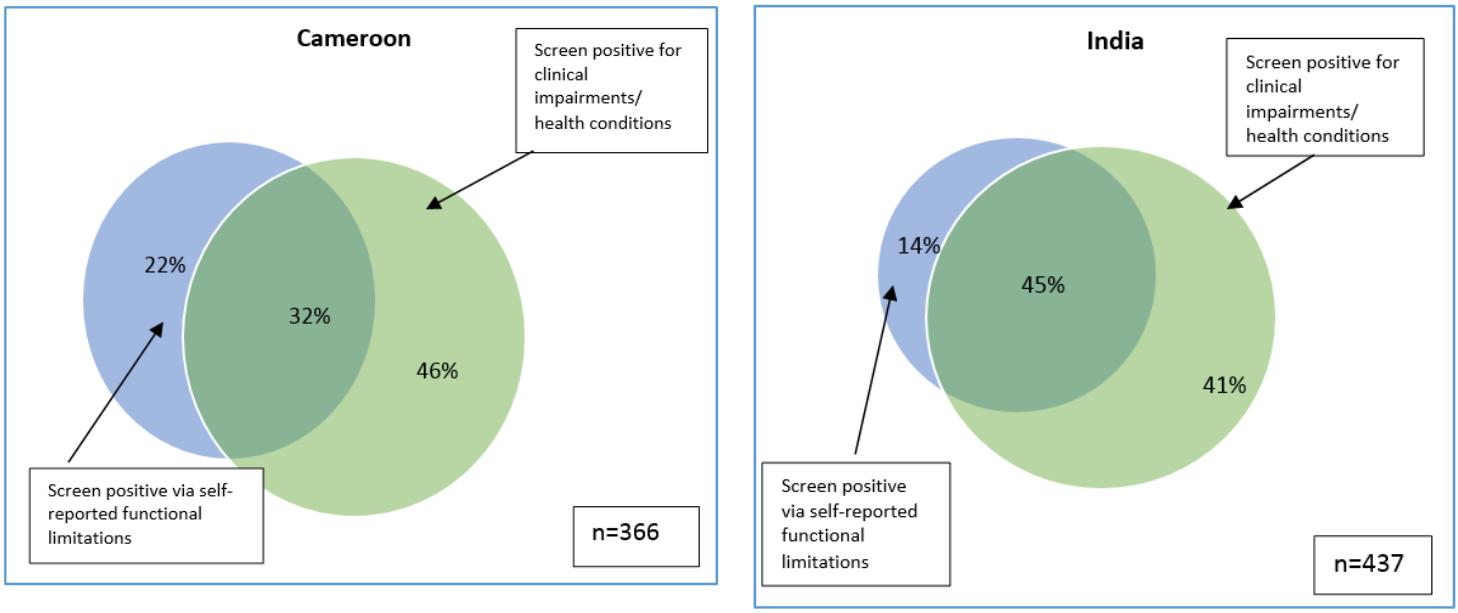
Disability: Any one of the above

Table 1: Overall Prevalence of Disability – India and Cameroon				
	India		Cameroon	
	n	% (95% CI)	n	% (95% CI)
Any disability	**437**	**12.2 (10.6-14.1)**	**373**	**10.5 (9.0-12.2)**
Self-Reported Activity Limitation	258	7.5 (5.9-9.4)	197	5.9 (4.7-7.4)
Any clinical impairment/ disabling health condition	376	10.5 (9.4-11.7)	294	8.4 (7.5-9.4)
Vision impairment	124	3.5 (2.7-4.4)	82	2.3 (1.8-3.0)
Hearing impairment	157	4.4 (3.7-5.2)	127	3.6 (2.8-4.6)
Physical impairment	125	3.5 (2.9-4.3)	123	3.4 (2.7-4.4)
Epilepsy	63	1.8 (1.4-2.2)	25	0.7 (0.5-1.0)
Depression (18+)	26	1.1 (0.7-1.6)	7	0.2 (0.09-0.4)
Multiple impairments	91	2.5 (2.1-3.1)	**59**	1.7 (1.2-2.1)
Single Question	135	3.8 (2.9-4.9)		-

Table 2 : Overall Prevalence of Disability by age and gender – India and Cameroon				
	India		Cameroon	
	n	% (95% CI)	n	% (95% CI)
0-17 years*	44	3.6 (2.6-4.9)	91	4.7 (3.7-5.9)
18-49 years	137	8.1 (6.0-11.0)	68	6.9 (5.3-9.1)
50+ years	256	38.3 (33.6-43.3)	214	33.6 (28.8-38.9)
Male	199	11.7 (9.7-14.0)	144	9.9 (8.3-11.7)
Female	238	12.2 (10.9-14.8)	229	10.8 (9.0-13.0)

***self report is 2-17 only**

Fig 2: Relationship between disability measures in Cameroon and India



Key Findings:

1) Disability Prevalence

- Overall disability prevalence is 12.2% in India and 10.5% in Cameroon
- Prevalence of significant activity limitations is 7.5% in India and 5.9% in Cameroon, and prevalence of moderate/severe clinical impairments and disabling health conditions is 10.5% in India and 8.4% in Cameroon
- Prevalence of disability and its components substantially increases with age in both countries, to 38.3% of adults over 50 in India, and 33.6% of adults over 50 in Cameroon identified to have a disability

2) Measuring Disability

- 45% of people identified to have a disability in India, and 32% of those in Cameroon, both reported a significant activity limitation and screened positive for a moderate/severe clinical impairment or disabling health condition (Fig. 2).
- 14% of those identified to have a disability in India and 22% in Cameroon screened positive via self-report only. Amongst these, most had mild clinical impairments and/or reported limitations not measured clinically (eg. Understanding, self care)
- 41% of people identified to have a disability in India and 46% in Cameroon screened positive for a moderate/severe clinical impairment or disabling health condition, but did not self-report having a significant functional limitation. Participants were less likely to report activity limitations in hearing or vision than MSI, and were less likely to report moderate clinical impairments than severe/profound impairments
- Using a single question in India led to a much lower estimates (3.8%) than either self-reported activity limitations or clinical impairments/health conditions.

3) Impact of Disability

- People with disabilities in India and Cameroon experienced significantly 1.4-1.8 times more participation restrictions than people without disabilities across all domains of participation.
- People who screened positive for clinical impairments reported significantly higher restrictions in participation if they also self-report activity limitations.
- Children with disabilities are less likely to go to school than children without disabilities (51% vs 91% in India, and 60% vs 97% in Cameroon), 6 times more likely to have repeated the same class in India, and 2.8 times more likely to have repeated a class in Cameroon
- Adults with disabilities are less likely to be working (44% vs 80% in India and 46% vs 78% in Cameroon) and twice as likely to have experienced a serious health condition in the previous 12 months than adults without disabilities in both countries
- Adults with disabilities aged 18-49 are nearly 3 times more likely to be in the poorest quarter than adults without disabilities in both countries, whilst both countries showed less relationship between poverty and disability amongst adults aged 50+
- Cross-cutting barriers identified in the qualitative work in Cameroon were those created by the natural environment, lack of access to information and fragmented rehabilitation services
- Cross-cutting enablers included strong familial and community support to facilitate participation and access to health-services and livelihoods

"Yes I like it [community Self Help Group]. Whenever we go there we share ideas about our feelings and conditions, and when I come back to the house I don't feel lonely any longer" – participant who is 43 and blind, Cameroon

"I hoped this wheelchair was going to help her even go to church, but she can't because it's difficult to climb here." – Mother of 33 year old with severe physical impairment, Cameroon

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 (this would identify 94% of people with disabilities in Cameroon and 95% in India)
3. Measures of participation should also be included to fully capture disability in programmes and surveys.

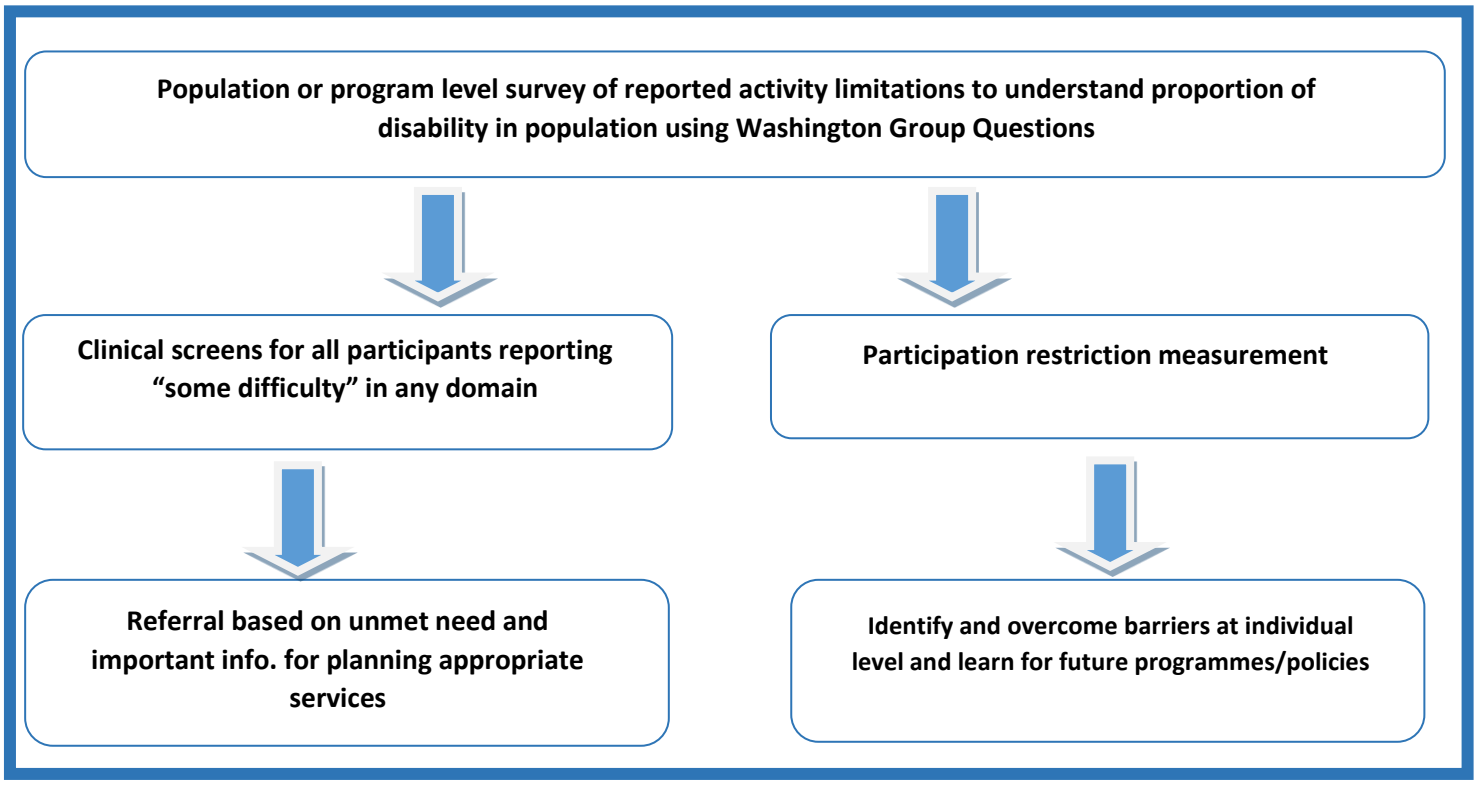


Fig 3: Recommended Disability Measurement Methodology

Recommendations for Disability Inclusion in India and Cameroon:

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 North West Cameroon, 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 in Telengana State and North West Cameroon and particularly to ensuring appropriate methods of education that allow disabled children to progress through school
3. 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
4. To understand the differences in estimates derived from different methodologies of disability measurement, and the most appropriate measures for programs and surveys

References:

1. The United Nations. *Convention of the Rights of Persons with Disabilities and Optional Protocol*. 2008 [cited 2012 01.05.12].
2. World Health Organization, *Towards a Common Language for Functioning, Disability and Health ICF*. 2002.

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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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