International Centre for Evidence in Disability

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

# Measuring Disability in Surveys and Programmes
# A Summary

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**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 is advocated by WHO World Report on Disability and ongoing Post 2015 debates
- There are no clear recommendations on how to do this in practice in a comprehensive way in surveys and programmes

**Defining Disability**

The International Classification of Functioning, Disability of Health (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.

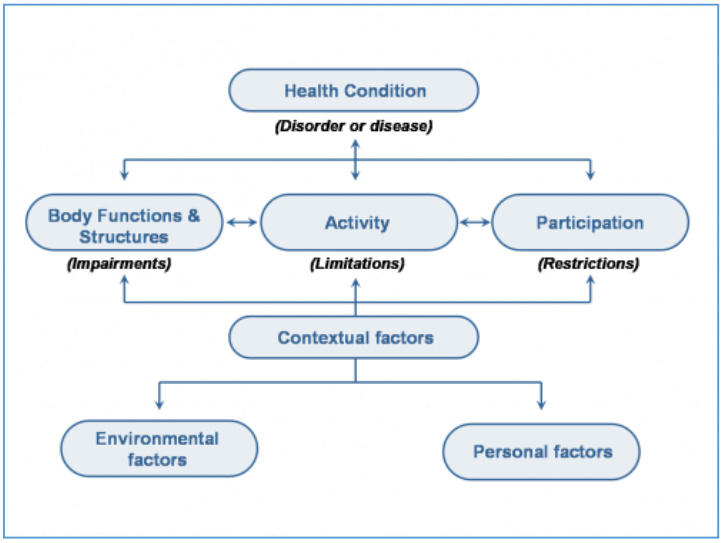



Fig 1: ICF Framework of disability
*Source: Rehab-scales.org*

The ICF is used to define disability in the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as

"long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder [a person's] full and effective participation in society on an equal basis with others"[1].

An example of what it means in practice is given in Table 1.

**Table 1 – Defining the ICF model of disability**

| Component of ICF definition of disability | Definition | Example |
|---|---|---|
| Impairments in body function or structure | Impairments in physiological functioning or anatomical parts of the body | Acute muscular weakness and limb paralysis |
| Activity Limitations | Limitations in the execution of tasks or actions by an individual | Not physically able to walk |
| Participation Restriction | Problems experienced in involvement in life situations | Local school is not accessible due to walking distance from the house |

*Cover photo: Young girl waits for screening, India*

**Measuring Disability:**

A number of different methods for measuring disability exist (Table 2), each focusing on a specific component of disability within the overall framework outlined on page 1.

**Table 2: Methods for measuring disability**

| Type | Example | Pros | Cons |
|---|---|---|---|
| Direct Questioning | "Do you have a disability?" | - Rapid<br>- Limited Space | - Underreport (stigma + lack of self-identification) |
| Self-reported activity limitation | "Do you have difficulty in seeing?" | - Simple to administer<br>- Info on experience/impact | - Does not assist planning for services/interventions/needs assessment |
| Self-reported participation restriction | "Do you have difficulty taking care of personal objects?" | - Info on what the person is able to do in their current environment | - Does not provide any information on underlying causes of restrictions |
| Clinical screening for impairments in body function and structure | Visual Acuity measurement | - Info on impairment type, severity and causality for intervention | - Resource intensive<br>- Impairment only one component of disability |

No previous studies have compared how the different approaches to measuring disability outlined above inter-relate.

**Study Aim:**

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 (Cameroon and India).
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

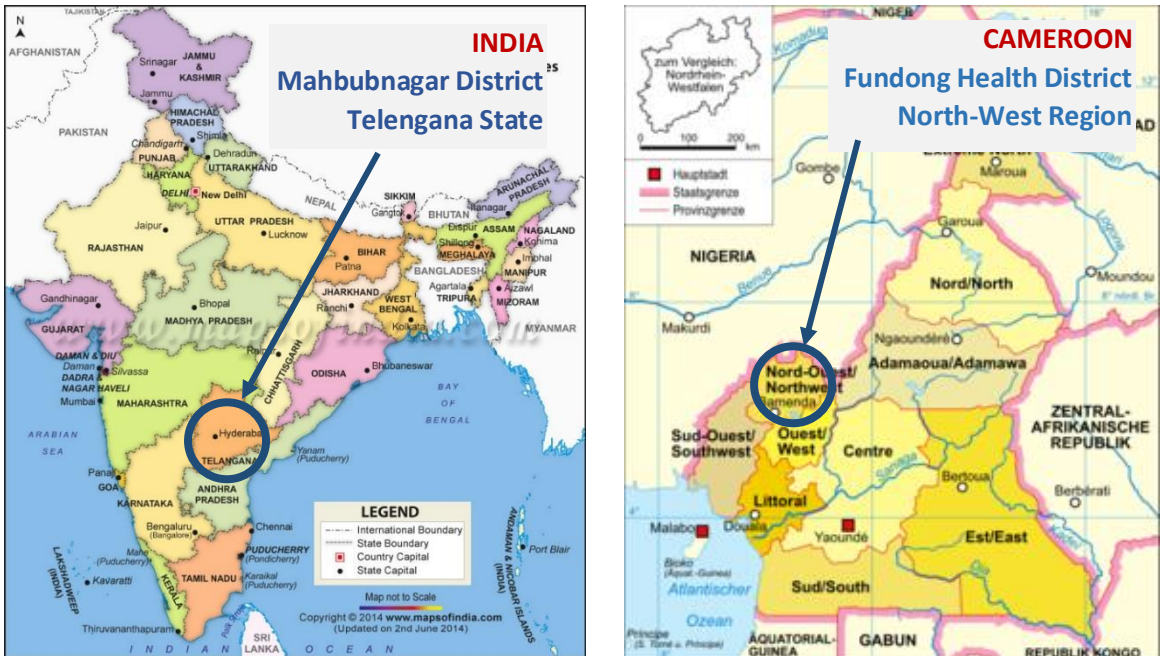



Fig. 2: Study Settings in India and Cameroon

**Study Design:**

1) Population-based survey of disability (n=4080, all ages) in Mahbubnagar District (India) and Fundong Health District (Cameroon)
2) Nested case-control study of people with and without disabilities

Disability screening Protocol outlined in Table 3

**Table 3: Disability Measurement Protocol**

| Component | Tool | Age | Screen Protocol |
|---|---|---|---|
| Self-reported activity limitation | Washington Group/UNICEF child functioning module | 2-7<br>8-17 | Child's functioning (14 questions through proxy-respondent)<br>Child's functioning (14 questions – child reported) |
| | Washington Group Extended Set on Functioning for Adults | ≥18 | Screening Questions on self-reported functional limitations and severity of limitation (12 Questions) |
| Visual Impairment | Rapid Assessment of Avoidable Blindness | 0-2<br>2-4<br>≥5 | Fix and Follow<br>Finger counting<br>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 |
| Hearing Impairment | WHO/PBD Ear and Hearing Disorders Examination protocol | 0-3<br>**≥4** | Oto-Acoustic Emission Testing<br>Oto-Acoustic Emission Testing and Pure Tone Audiometry |
| Musculoskeletal impairment and Epilepsy | Rapid Assessment of Musculoskeletal Impairment (RAM) | 0-7<br><br><br><br>**≥8** | Screening Questions on the musculoskeletal system, use of aids and history of seizures directed to proxy respondent (7 Questions)<br><br>Screening Questions on the musculoskeletal system, use of aids and history of seizures (7 Questions) |
| Clinical Depression | Patient Health Questionnaire (PHQ9) | **≥18** | Screening Questions on symptoms and severity (9 Questions) |

**Definition of disability used in the study:**
Screening criteria used to identify persons with disabilities from the population-based sample and for inclusion in the case-control study 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**

**Results: Measuring Disability**

Tables 3 and 4 present disability prevalence in India and in Cameroon. In India, there is also an estimate for disability using a single question "Do you consider yourself/your child to have a disability" for reference.

**Main findings:**

- Overall disability prevalence is 12.2% (95% CI 10.6-14.1) in India and 10.5% in Cameroon (95%CI 9.0-12.2).
- Prevalence of significant activity limitations is 7.5% (95% CI 5.9-9.4) in India and 5.9% in Cameroon (95% CI 4.7-7.4).
- Prevalence of moderate/severe clinical impairments and disabling health conditions is 10.5% (95% CI 9.4-11.7) in India and 8.4% (95% CI 7.5-9.4) in Cameroon
- Overall prevalence of disability, and its components – activity limitations and clinical impairments – is similar, but slightly higher, in India for all components than in Cameroon
- 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.

**Predictors of disability:**

- The prevalence of disability and its components substantially increases with age, to 38.3% of adults over 50 in India, and 33.6% of adults over 50 in Cameroon identified to have a disability

Figures 3 and 4 present the relationship between activity limitations and clinical impairments amongst those identified to have a disability in the study.

- 45% of people identified to have disabilities 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

➔ Using self-report only identified 49% people with disabilities in India, and 54% in Cameroon
➔ Using clinical measures only identified 86% of people with disabilities in India, and 78% in Cameroon

People identified with disabilities on self-report only:

- 14% of people identified to have disabilities in India, and 22% of those in Cameroon, screened positive for self-reported significant activity limitation but not a moderate/severe clinical impairment or disabling health condition.
- In India, amongst the group who screened positive via self-report only (n=61), 74% screened positive for a mild clinical impairment and 26% reported activity limitations that were not measured clinically (such as learning, understanding, remembering and self-care).
- In Cameroon, amongst those who screened positive via self-report only (n=79), 61% screened positive for a mild clinical impairment, 27% reported difficulties in domains not directly screened clinically and 13% reported difficulties in domains that were clinically evaluated not to be impaired (hearing and walking).

People identified with disabilities on clinical screen only:

- The remaining 41% of people identified to have disabilities in India, and 46% in Cameroon, screened positive for a moderate/severe clinical impairment or disabling health condition, but did not self-report as having a significant functional limitation.
- In both countries, participants with impairments were more likely to report activity limitations if:
    - Impairment was severe or profound
    - Impairment was MSI rather than hearing or vision.
- Qualitative work related to this study shows that domains of function most related to livelihood and participation are considered more important by communities.

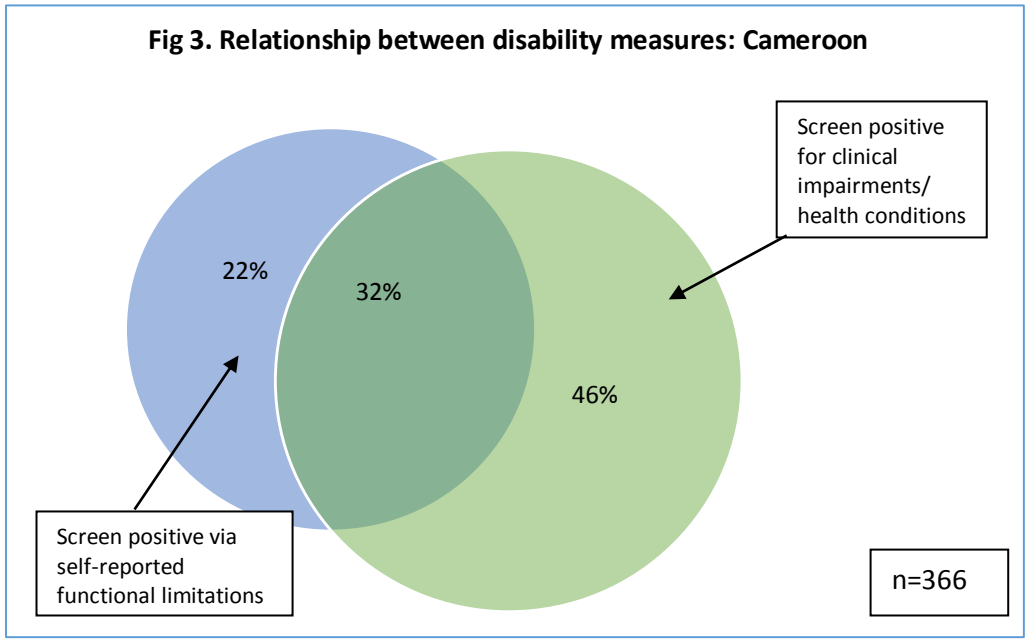
Tables 5 and 6 present estimates of participation restriction amongst people with and without disabilities. For each domain in each age group, the mean score is calculated against the maximum total score possible for that domain (max. score= answering “unable to do” to each question in that domain). Key findings were that:

- People with disabilities in India and Cameroon experienced 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 higher restrictions in participation if they also self-reported activity limitations.

| Table 3: 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 4: Overall Prevalence of Disability by age and gender – India and Cameroon | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 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) |
| **India** | 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) |
| **Cameroon** | 373 | 10.5 (9.0-12.2) | 91 | 4.7 (3.7-5.9) | 68 | 6.9 (5.3-9.1) | 214 | 33.6 (28.8-38.9) | 144 | 9.9 (8.3-11.7) | 229 | 10.8 (9.0-13.0) |
| ***self report is 2-17 only** | | | | | | | | | | | | |

*Photos: Left, enumeration in Cameroon. Right, screening for self-reported limitations in India*



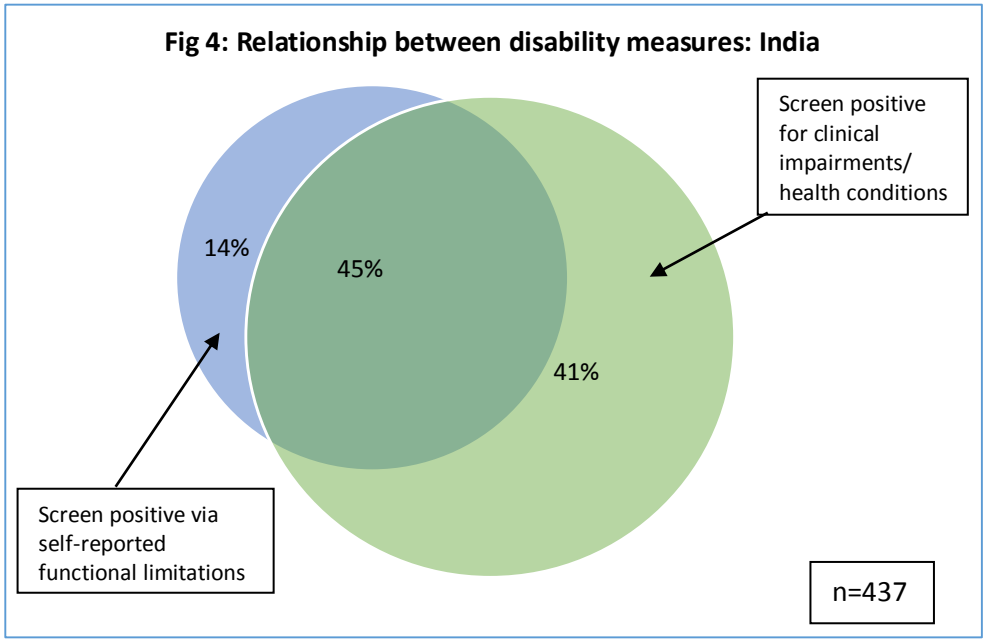




**Table 5: Participation Restrictions in India and Cameroon**

| | | India | | | | | Cameroon | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Max score | Controls (mean) | All Cases (mean) | Clinical with no self report | Clinical plus self report | P* | Controls (mean) | All Cases (mean) | Clinical with no self report | Clinical plus self report | P* |
| Age 5-8 | 40 | 12.8 | 22.0 | 18.7 | 22.4 | 0.59 | 13 | 16.5 | 11 | 17.7 | 0.1 |
| Age 9-16 | 60 | 17.1 | 36.44 | 22.6 | 39.1 | <0.01 | 17 | 26.1 | 19.3 | 30.7 | <0.001 |
| Age 17-33 | 84 | 24.5 | 39.8 | 28.9 | 47.2 | <0.001 | 25.3 | 34.7 | 29.7 | 40.8 | <0.01 |
| Age 34-49 | 84 | 30.8 | 11.7 | 32.4 | 38 | 0.07 | 25.4 | 36 | 33.5 | 42.7 | 0.14 |
| Age 50-65 | 84 | 28.3 | 39.8 | 35.4 | 43.9 | <0.001 | 26.4 | 31.9 | 32.4 | 35.8 | 0.23 |
| Age 66+ | 84 | 34.6 | 49.7 | 39.3 | 53.5 | <0.001 | 28.3 | 33.8 | 31 | 38 | <0.001 |

* Independent-samples t-test conducted to compare means between clinical cases who did/ did not report significant activity limitations. A separate independent-samples test was conducted to compare means between all cases and all controls, and the difference between means was statistically significant across all age groups in both countries (not shown).

**KEY FINDINGS:**

1. **Prevalence estimates for disability (defined as any individual with a significant activity limitation, moderate/severe clinical impairment or disabling health condition) in Cameroon and India were similar and increased substantially in both countries with age**
2. **Using a self-reported activity limitation tool alongside clinical tools to measure specific impairments and health conditions showed a high proportion of participants screening positive to moderate/severe clinical impairments and health conditions but not reporting significant activity limitations**
   - ➔ **Some moderate impairments and some impairments that have lower impact on participation in a particular context (eg. hearing impairment in a rural, farming community) may be missed by self-report tools**
   - ➔ **Less participation restrictions are reported amongst those who have not reported a significant activity limitation than those who have, but these restrictions are still higher than people without any clinical impairments**
3. **Using a single question on disability leads to significant under-reporting and is not recommended**

**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. 5 depicts this in practice and the justification for using particular tools in either a population-survey or programme setting

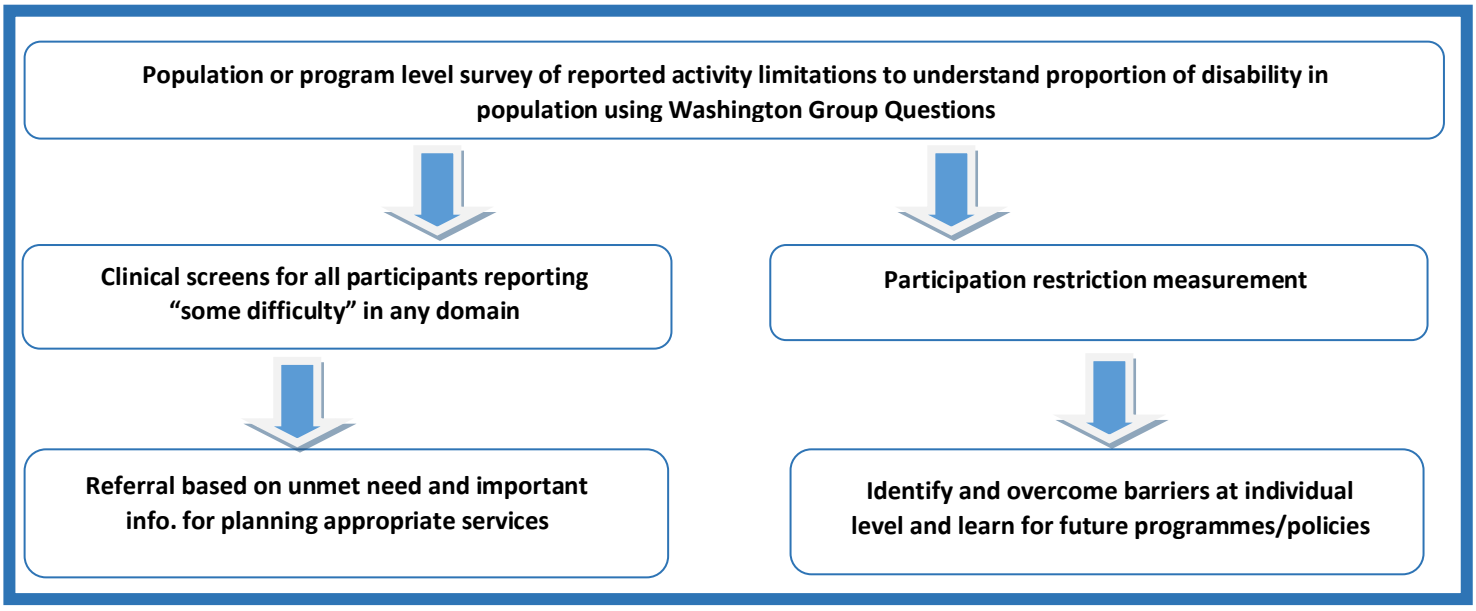



*Fig 5: Recommended Disability Measurement Methodology*

*Photo: Mothers wait with their children at village screening sessions*

**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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