

WG/UNICEF Survey Module on Child Functioning and Disability

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collaboration with UNICEF

Background (1)

- UN Convention on the Rights of the Child (1989)
- UN Convention on the Rights of Persons with Disabilities (2006)
- International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) (WHO, 2007)
- UN 66th General Assembly (2011) and the resolution on the Rights of the Child

set the international background for collecting data on childhood disability.

Background (2)

The quality and quantity of data available on child disability varies enormously across the world due to:

1. the priority given to disability issues in the political agenda
2. the level of local resources available
3. cultural factors (such as differences in values and attitudes towards individuals with disabilities)
4. several aspects related to data collection

↪ **NO International comparability**

Task:

To develop and test a survey module specifically designed to capture child functioning and disability.

Challenge:

Several reasons why measuring disability for children is different than for adults:

- Children are in a process of development and transition – not all of the 6 domains in the WG Short set are applicable to young children
- Child development does not follow a fixed schedule – there is natural variation in the attainment of functional skills
- Disability measurement often takes place through the filter of a parent or other adult.

Primary purpose of the module:

to identify the sub-population of children and youth (aged 2-17 years) who are “at greater risk” than the children of the same age of experiencing limited social participation.

A major reason for this choice is the crucial importance of the issue of social participation and equal rights from a policy perspective as illustrated in the UN Convention on the Rights of Persons with Disabilities and in the UN Convention on the Rights of the Child.

The aim of the module:

- to provide cross-nationally comparable data.

The Module is intended to be used as a component of national population surveys or as supplement to surveys on specific topics of interest (health, education, etc.).

A set of questions was drafted following these guidelines:

- avoid a medical approach
- use the ICF bio-psycho-social model
- use, when appropriate, questions already tested and/or adopted by the WG;
- include the reference “Compared with children of the same age...” where appropriate
- consider age specificity when constructing questions
- response options to reflect disability continuum.

Use of measures of child functioning and disability

Describe the population at risk – to inform policy.

Classify the population to monitor disparities in participation by disability status (also provides a prevalence rate).

Identify a population for 2nd stage assessment. (Improve our understanding of population data.)

To provide services to children indentified.

Cognitive Training/Testing:

Sites:

- September 2012, Mumbai, India
- January 2013, Belmopan, Belize
- April 2013, Muscat, Oman
- July 2013, Podgorica, Montenegro

Analysis:

- Individual country reports
- Larger, unified analysis (N=224)

Overview of Primary Findings

- Child disability questions perform differently than adult disability questions
- Primarily in 2 ways:
 - Parental proxy
 - Parent's knowledge of "what is normal" - comparing to other children the same age

Overview of Primary Findings

- Parent proxy reports:
 - Parent expectations
 - Relationship between parent and child
 - Potential for False Positives
 - Domains most effected: those that generate parent frustration (Learning/remembering, communication, Attention/completing a task)

Overview of Primary Findings

- Comparing with children the same age
 - Respondents do not always make this comparison
 - Domains most effected: those that children do without other children; those that are isolated or internal activities (Self-care, Emotions, Attention)

Preamble

The next questions ask about difficulties your child may have in doing certain activities...

Response options:

Unless noted otherwise, all response categories are:

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

- 7) Refused
- 9) Don't know

Seeing

Children aged 2-17 years

1a) Does [name] wear glasses?

Yes/No

[If child wears glasses]

1b) When wearing [his/her] glasses, does [name] have difficulty seeing?

Would you say... *[Read response categories]*

[If child does NOT wear glasses]

1b) Does [name] have difficulty seeing?

Would you say... *[Read response categories]*

Hearing

Children aged 2-17 years

2a) Does [name] use a hearing aid?

Yes/No

[If child uses a hearing aid]

2b) When using [his/her] hearing aid(s), does [name] have difficulty hearing?

Would you say... *[Read response categories]*

[If child does NOT use a hearing aid]

2b) Does [name] have difficulty hearing?

Would you say... *[Read response categories]*

Walking

Children aged 2-17 years

Does [name] use any equipment or receive help for walking?

Yes/No

Walking

Children aged 2-4 years

[If child uses equipment or receives help]

3a1) Without the use of any equipment or assistance, does [name] have difficulty walking?

Would you say... *[Read response categories; do not include No difficulty]*

[If child does NOT use equipment or receives help]

3a2) Compared with children of the same age, does [name] have difficulty walking?

Would you say... *[Read response categories]*

Walking

Children aged 5-17 years

[If child uses equipment or receives help]

3b1) Without the use of any equipment or assistance, does [name] have difficulty walking 100 yards/ meters on level ground? That would be about the length of 1 football field. *[Or insert country specific example]*.

Would you say... *[Read response categories do not include No difficulty]*

If Cannot do at all, skip to Self-care

Walking

Children aged 5-17 years

[If child uses equipment or receives help]

3c1) Without the use of any equipment or assistance, does [name] have difficulty walking 500 yards/ meters on level ground? That would be about the length of 5 football fields. *[Or insert country specific example]*.

Would you say... *[Read response categories do not include No difficulty]*

Walking

Children aged 5-17 years

[If child does not use equipment or receives help]

3b2) Compared with children of the same age, does [name] have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. *[Or insert country specific example]*.

Would you say... *[Read response categories]*

If Cannot do at all, skip to Self-care

Walking

Children aged 5-17 years

[If child does not use equipment or receives help]

3c2) Compared with children of the same age, does [name] have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. *[Or insert country specific example]*.

Would you say... *[Read response categories]*

Self-care

Children aged 5 - 17 years

4) Does [name] have difficulty with self-care such as feeding or dressing [him/herself]?

Would you say... [*Read response categories*]

Communication/Comprehension

Children aged 2-4 years

5a) Does [name] have difficulty understanding you?

Would you say... [*Read response categories*]

6a) Do you have difficulty understanding your child?

Would you say... [*Read response categories*]

Communication/Comprehension

Children aged 5-17 years

5b) Compared with children of the same age, does [name] have difficulty understanding other people?

Would you say... [*Read response categories*]

6b) Compared with children of the same age, does [name] have difficulty being understood by other people?

Would you say... [*Read response categories*]

Learning

Children aged 2-3 years

7a) Compared with children of the same age, does [name] have difficulty learning the names of common objects?

Would you say... [*Read response categories*]

Learning

Children aged 2-17 years

7b) Compared with children of the same age, does [name] have difficulty learning new things?

Would you say... [*Read response categories*]

Learning

Children aged 5-17 years

8) Compared with children of the same age, does [name] have difficulty remembering things?

Would you say... [*Read response categories*]

Emotions

Children aged 5-17 years

9) How much does [name] worry or feel sad?

Would you say... [*Read response categories*]

- 1) Not at all
- 2) A little
- 3) A lot
- 4) Somewhere in between a little and a lot

Behavior

Children aged 2-4 years

10) Compared with children of the same age, how much does [name] kick, bite or hit other children or adults?

Would you say... [*Read response categories*]

- 1) Not at all
- 2) The same or less
- 3) More
- 4) A lot more

Behavior

Children aged 5-17 years

10) Compared with children of the same age, how much difficulty does [name] have controlling his/her behaviour?

Would you say... [*Read response categories*]

- 1) None
- 2) The same or less
- 3) More
- 4) A lot more

Attention

Children aged 5-17

11) Does [name] have difficulty focussing on an activity that [he/she] enjoys doing?

Would you say... [*Read response categories*]

Coping with change

Children aged 5-17 years

12) Does [name] have difficulty accepting changes in [his/her] routine?

Would you say... [*Read response categories*]

Playing

Children aged 2-4 years

13) Compared to children of the same age, does [name] have difficulty playing?

Would you say... [*Read response categories*]

Relationships

Children aged 5-17 years

14) Does [name] have difficulty making friends?

Would you say... [*Read response categories*]