

The WG/UNICEF Module on Child Functioning

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Topics covered

Why do we need data on child disability

Why data available on child disability are not internationally comparable

Why it is difficult to measure disability in child through population surveys

How the Module on child functioning was developed and validated

Main characteristics of the Module

Why do we need data on child disability? (1)

Raise awareness. Consistent and accurate data helps bring attention to this population by demonstrating the extent and impact of disability among children.

Advocate for the rights of CwD. Accurate data can provide strong support for advocacy efforts because it helps justify the need for change and for increase resources for appropriate interventions.

Quantify needs. Reliable data can identify the number of children with disability as well as assess their unmet needs and therefore to identify gaps in services that must be addressed.

Why do we need data on child disability? (2)

Prioritize interventions. Data can provide decision-makers with basic information that can be used to determine priorities related to child disabilities and their families.

Monitor progress. Collecting consistent data over time can be used to monitor outcomes on national policies and interventions in order to expand effective programs and modify/delete ineffective ones and to fulfill the requirements of the UN Conventions and the Sustainable Development Goals (SDGs).

Data on child disability varies widely across the world due to:

1. different priority given to *children* and/or to *disability* in the political agenda at national level
2. different level of local resources available for data collection at national level
3. cultural factors (such as differences in values and attitudes towards individuals with disabilities) influence reporting child disability in the surveys
4. lack of a standardized approach to data collection (such as definition of disability, purpose of measurement, data collection method...)

The result is: **No international comparability**

Main factors affecting the international comparability of survey data (1)

- Questions specifically designed to assess child disability vs questions designed for adults and also used for children
- Questions that ask about the presence of disability vs questions on type of impairment or difficulties in functioning
- Aspects investigated: domains and features

Main factors affecting the international comparability of survey data (2)

- Age range of target population
- Answer categories: dichotomous vs multiple response categories according to a severity scale
- Severity scales: different types and number of items are used and the threshold selected may be different
- In reporting prevalence, children are grouped by different age ranges

Challenge:

Defining disability in children is far more difficult than in adults:

- *Children are in a constant developmental process that implies continuous changes in their ability to perform actions and activities, especially in the early ages*
 - *Child development does not follow a fixed schedule: milestones of development can be reached by children at different ages*
 - not all of the 6 WG short set domains are applicable to young children
 - nor do they cover the full range of domains of particular interest in child development
 - *Disability measurement often takes place through the filter of a parent or another adult*
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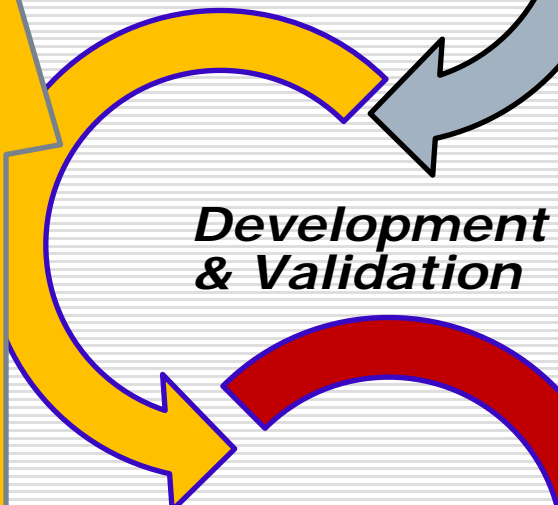
Objectives

- **Purpose**
 - To identify the sub-population of children (aged 2-17 years) with functional difficulties. These difficulties may place children at risk of experiencing limited participation in a non-accommodating environment.
- **Aim**
 - To provide cross-nationally comparable data
 - To be used as part of national population surveys or in addition to specific surveys (e.g., health, education, etc.)

Development of the Module: main steps

The **WG-UNICEF Child Functioning Working Group** (NSO reps. from both developed and developing countries) followed these main steps in developing the Module:

- Established guiding principles
- Reviewed literature
- Assessed existing questions/tools
- Consulted child development specialists/ other survey methodologists



- Drafted/revised the questions
- Conducted Multiple rounds of CT
- Finalized the questions
- Conducted Field Tests
- Finalized the Module

- Developed interviewer guidelines/user manual
- Professional translation of the module
- Planned capacity building activities

Guiding principles for drafting the questions (1)

- to avoid a medical approach and use the ICF bio-psycho-social model of disability
- to measure “difficulties in functioning”
- to select basic actions and activities that can identify the main types of functional limitations in children
- to propose age-specific questions
- to formulate questions that are culturally relevant and able to collect comparable data cross-nationally

Guiding principles for drafting the questions (2)

- to adopt, where applicable, questions already tested including those of the WG short and extended sets
- to use answer categories able to get the severity of the activities limitation in order to reflect the disability continuum
- to include, when appropriate, the reference “Compared with children of the same age...”
- to ask questions to parents or primary caregivers.

Selected domains

1. Seeing*
2. Hearing*
3. Mobility**
4. Self-care (5-17)*
5. Dexterity (2-4)
6. Communication*
7. Learning
8. Remembering (5-17)*
9. Emotions (5-17)**
10. Behaviour
11. Attention (5-17)
12. Coping with change (5-17)
13. Relationships (5-17)
14. Playing (2-4)

* Comparable WG SS questions 13

** Comparable WG ES questions

Content and structure

- *Preamble*: I would like to ask you some questions about difficulties your child may have
- Unless noted otherwise, all response categories are:
 - No difficulty
 - Some difficulty
 - A lot of difficulty
 - Cannot do at all
- Questions on vision/hearing and mobility include questions on the use of glasses/hearing aids/ assistance with walking

Cognitive & Field Testing

- **Cognitive testing** determines if respondents understand the question as intended
 - Do individual respondents understand the survey question differently?
 - Does the question mean the same in all the languages, cultures and socio-economic groups?



To evaluate the cross-cultural equivalence of the module

- **Field testing** provides evidence to better understand the extent to which patterns exist in a population

Cognitive Testing

- Cognitive testing:
 - September 2012, India
 - January 2013, Belize
 - April 2013, Oman
 - July 2013, Montenegro
 - 2012/13/14/15/16, USA
 - March 2016, India
 - April 2016, Jamaica
- Comparative report completed and decisions made on final set of questions included in field testing

Cognitive Testing Findings

Parent proxy:

- Parent's knowledge of "what is normal" for children of the same age
- Relationship between parent and child
- Parental frustration with child

Compared to children of the same age

Cognitive testing: An Example

Hearing domain

Round #1

DOES [NAME] HAVE DIFFICULTY HEARING?

- This question is intended to focus on auditory hearing: that is, the physical capability of the child to hear.
 - Many respondents, however, focused on listening: “my child doesn’t listen to me when I’m speaking”.
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Cognitive testing: An Example

Hearing domain

Round #2

DOES [NAME] HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES'
VOICES OR MUSIC?

The second round of cognitive testing indicated that this phrasing clarified the confusion between the auditory process of “hearing” and “listening”.

Field Testing (2013-2016)

- *Independent field testing* on earlier versions of the module or subset of questions completed in Haiti (Brown University, 2013), Cameroon & India (London School of Hygiene and Tropical Hygiene, 2013), and Italy (NSO, 2013)
- *Field testing of complete version* of the module in Samoa (NSO, 2014) and El Salvador (NSO, 2015) with technical assistance from UNICEF/WG
- *Module also used in surveys* in Zambia (National Disability Survey, NSO, 2014) and Mexico (MICS, 2016)
- *Dedicated methodological work* in Serbia (NSO, 2016)

Field Testing Findings

- Questionnaire generally administered without any major problems by interviewers
- Reactions of the respondents were mostly neutral to positive
- Repetitive to read out loud response categories
- Module able to capture moderate to severe forms of difficulties, not mild (some difficulty leads to false positive)

Field testing/Data analysis

Three levels of difficulty defined:

	Children age 2-4	Children age 5-17
Level 1: Mild to Severe	<ul style="list-style-type: none"> At least 1 domain is some difficulty, a lot of difficulty or cannot do at all Controlling behavior: coded more or a lot more 	<ul style="list-style-type: none"> At least 1 domain is some difficulty, a lot of difficulty or cannot do at all Anxiety and Depression: coded weekly or daily
Level 2: Moderate to Severe	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all Anxiety and Depression: coded daily
Level 3: Severe	<ul style="list-style-type: none"> At least 1 domain is cannot do at all Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is cannot do at all Anxiety and Depression: coded daily

Field testing: Initial Results

Disability Prevalence Rate by Different Cut-offs			
	Mexico	Samoa	Serbia
Level 1: Mild to severe			
Age 2-4	27.5	15.5	11.5
Age 5-17	46.3	9.3	25.2
All Ages	40.5	10.4	24.9
Level 2: Moderate to severe			
Age 2-4	5.4	2.8	3.8
Age 5-17	14.1	3.3	4.5
All Ages	11.4	4.0	4.3
Level 3: Severe difficulty			
Age 2-4	0.4	0.8	0.0
Age 5-17	6.5	2.4	2.2
All Ages	4.6	1.9	1.9
Number aged 2-4	5153	2139	219
Number aged 5-17	11607	7426	1250

Next steps

- Finalization and release of interviewer guidelines – 2017
- Publication of field test results – 2017
- Finalisation of manual for implementation - 2017

UNICEF-WG workshops on child disability measurement across the world

Final remarks

- The **UNICEF-WG Module on Child Functioning** was developed in response to an internationally recognized need of comparable data.
- It was built up with input from a variety of experts and stakeholders to be in line with the ICF and UNCRPD concept of disability.
- It has undergone a series of cognitive and field tests that have proven the questions to be straightforward to administer and well understood by respondents across contexts and cultures.

Main references

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Discussion
