

The WG/UNICEF Module on Child Functioning



Mitchell Loeb

National Center for Health Statistics, USA and
Washington Group on Disability Statistics

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

1. different priority given to *children* and to *disability* in the political agenda at national level
2. different 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, different age-group bands, etc.)

The result is: No international comparability

Why do we need data on child disability?

Understand the situation of children with disabilities:

prevalence, social circumstances and geographic location, unmet needs and the quality of the support they are receiving.

Assess the role of environmental factors (including societal attitudes and physical barriers) in the experience of disability.

Advocate for the rights of children with disabilities.

Prioritize interventions: inform policies and programs, facilitate the planning of services, and improve participation and quality of life of children with disabilities and their families.

Monitor progress on the UN Convention on the Rights of People with Disabilities (CRPD) and Convention on the Rights of the Child (CRC).

Challenge:

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

- Children are in a process of development and transition
 - 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
- 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.

UNICEF/WG Collaboration

- Objective of Collaboration: To develop and test a survey module specifically designed to capture child functioning
- 2009 - Workgroup on Child Functioning and Disability created
- 2011 - UNICEF joined the workgroup and began collaborating with the WG

Objectives

- Purpose
 - To 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.)

Principles

- Avoided a medical approach
- Used the ICF biopsychosocial model
- Used, when appropriate, questions already tested and adopted by the WG
- Included the reference “Compared with children of the same age...”
- Considered age specificity
- Response options reflected disability continuum

History and development

- WG Workgroup on Child Functioning was established fall 2009 under the leadership of ISTAT (Italy)
- UNICEF joined the Workgroup in early 2011
- First draft module presented Nov. 2011 at 11th WG meeting in Bermuda
- April 2012: Rome technical meeting, revision of the module
- June 2012: Technical Consultation on the Measurement of Child Disability meeting hosted by UNICEF
- October 2012: 12th WG meeting: presentation of the new module
- From September 2012 to April 2016: validation process

Content and structure

- Questions ask about difficulties the child may have in doing certain activities
- Unless noted otherwise, all response categories are:
 - No difficulty
 - Some difficulty
 - A lot of difficulty
 - Cannot do at all

Selected domains

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

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 that it is asked?
- Field testing provides evidence to better understand the extent to which patterns exist in a population

Cognitive Testing

- Cognitive testing
 - 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

Child disability questions perform differently than adult disability questions due to:

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

Field Testing (2013-2016)

- Independent field testing on earlier version 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
- Similar results in levels obtained in Serbia, Mexico and Samoa
- 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	<ul style="list-style-type: none"> At least 1 domain is some difficulty, a lot of difficulty or cannot do at all except 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 except Controlling behavior: coded more or a lot more and Anxiety and Depression: coded weekly or daily
Level 2: Moderate	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Controlling behavior: coded more or a lot more 	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Controlling behavior: coded more or a lot more and Anxiety and Depression: coded daily
Level 3: Severe	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Controlling behavior: coded a lot more and Anxiety and Depression: coded daily

Field testing: Initial Results

Disability Prevalence Rate by Different Cut-offs		
	Samoa	Serbia
Level 1: Mild difficulty		
Age 2-4	15.5	9.4
Age 5-17	9.0	25.0
All Ages	10.4	22.7
Level 2: Moderate difficulty		
Age 2-4	2.9	3.8
Age 5-17	4.3	3.5
All Ages	4.0	3.5
Level 3: Severe difficulty		
Age 2-4	0.8	0.0
Age 5-17	2.4	2.2
All Ages	1.9	1.9
Number aged 2-4	2135	219
Number aged 5-17	7422	1250

Seeing

Children aged 2-17 years

Does [name] wear glasses or *contact lenses?
Yes/No

[If child **wears** glasses]

When wearing [his/her] glasses or *contact lenses, does
[name] have **difficulty seeing**?

Would you say... [Read response categories]

[If child does **NOT** wear glasses]

Does [name] have **difficulty seeing**?

Would you say... [Read response categories]

*Only in 5-17 questionnaire

Hearing

Children aged 2-17 years

Does [name] use a hearing aid?
Yes/No

[If child **uses** a hearing aid]

When using [his/her] hearing aid, does [name] have **difficulty hearing sounds** like peoples' voices or music?

Would you say... [Read response categories]

[If child does **NOT** use a hearing aid]

Does [name] have **difficulty hearing sounds** like peoples' voices or music?

Would you say... [Read response categories]

Walking

2-4 years

Does [name] use any equipment or receive assistance for walking?
Yes/No

*If child **uses** equipment or receives assistance*

Without using his/her equipment or assistance, does [name] have **difficulty walking**? Would you say... *[Read response categories]*

01/06/2017

5-17 years

Does [name] use any equipment or receive assistance for walking?
Yes/No

*If child **uses** equipment or receives assistance*

Without using his/her 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]*

Without using his/her 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]*

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Walking: Continued

2-4 years

When using his/her equipment or assistance, does [name] have **difficulty walking**? Would you say...
[Read response categories]

5-17 years

When using his/her 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]

When using his/her 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]

Walking: Continued

2-4 years

*If child does **NOT** use equipment or receive assistance*

Compared with children of the same age, does [name] have **difficulty walking**? Would you say... [*Read response categories*]

01/06/2017

5-17 years

*If child does **NOT** use equipment or receive assistance*

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].

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*]

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Fine Motor

2-4 years	5-17 years
<p>Compared with children of the same age, does [name] have difficulty picking up small objects with his/her hand?</p> <p>Would you say... <i>[Read response categories]</i></p>	N/A

Self-Care

2-4 years	5-17 years
	<p>Does [name] have difficulty with self-care such as feeding or dressing [him/herself]?</p> <p>Would you say... <i>[Read response categories]</i></p>

Communication/Comprehension

2-4 years

Does [name] have difficulty **understanding you**?

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

When [name] speaks, does he/she have difficulty **being understood by you**?

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

01/06/2017

5-17 years

When [name] speaks, does he/she have difficulty being understood by **people inside of this household**?

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

When [name] speaks, does he/she have difficulty being understood by **people outside of this household**?

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

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Learning

2-4 years

Compared with children of the same age, does [name] have difficulty **learning things**?

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

5-17 years

Compared with children of the same age, does [name] have difficulty **learning things**?

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

Compared with children of the same age, does [name] have difficulty **remembering things**? Would you say... [*Read response categories*]

Emotions

2-4 years

N/A

5-17 years

How often does [name] seem very **anxious, nervous or worried?**
How often does [name] seem very **sad or depressed?**

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

- 1) Daily
- 2) Weekly
- 3) Monthly
- 4) A few times a year
- 5) Never

Behavior

2-4 years

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

01/06/2017

5-17 years

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

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Attention

2-4 years	5-17 years
N/A	<p>Does [name] have difficulty concentrating on an activity that [he/she] enjoys doing?</p> <p>Would you say... [<i>Read response categories</i>]</p>

Coping with Change

2-4 years	5-17 years
N/A	Does [name] have difficulty accepting changes in [his/her] routine? Would you say... [<i>Read response categories</i>]

Playing

2-4 years	5-17 years
<p>Compared to children of the same age, does [name] have difficulty playing?</p> <p>Would you say... [<i>Read response categories</i>]</p>	N/A

Relationships

2-4 years	5-17 years
N/A	Does [name] have difficulty making friends? Would you say... [<i>Read response categories</i>]

Next steps

- Release of finalised module and interviewer guidelines – June 2016
- Publication of field test results – end of 2016
- Finalisation of manual for implementation - end of 2016