

The WG Workgroup on Child Functioning and Disability

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The WG Workgroup on Child Functioning and Disability

- References to International background
- History of WG child group: meetings and other activities
- The module: how it was developed and its main characteristics

Working on Child Functioning and Disability: Background ⁽¹⁾

- **UN Convention on the Rights of the Child (1989)** is the first explicit provision relating to the rights of children with disabilities.

Article 2: no discrimination on the grounds of disability

Article 23: provide service ⇒ enable to achieve social integration

- **UN Convention on the Rights of Persons with Disabilities (2006)** further strengthened the rights of children with disabilities.

Article 7: Children with Disabilities

Article 31 - Statistics and data collection

- **International Classification of Health, Functioning and Disability (ICF, WHO 2001):** new definition of disability

Working on Child Functioning and Disability: Background (2)

- **UN 66th General Assembly (2011)** adopt a resolution that called upon the all States to fully implement the “Realizing the Millennium Development Goals for persons with disabilities towards 2015 and beyond” and “*to ensure that children with disabilities are rendered visible in the collection and analysis of data*”.
- **World Disability Report (WHO-World Bank, 2011)** recommended to develop appropriate instruments for measuring childhood disability.

All these set the international background for collecting and using data on childhood disability.

Working on Child Functioning and Disability: Background ⁽³⁾

The strategic importance of the **synergy between policies and statistical information** has been fully recognized at the national and international level.

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

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

➔ **NO International comparability**

Measuring child functioning and disability: Challenges

- Disability in children is far more difficult to define than in adult:
 - children are in a constant developmental process that implies continuous changes in their ability to perform activities, especially in the early ages
 - milestones of development can be reached with variation among children
- Type of disability in children is different from adult disability
- Disability measurement often takes place through the filter of a parent or other adult.

Questions used for adult are not always appropriate for children

Working on Child Functioning and Disability: progress and meetings (a)

1. Workgroup on Child Functioning and Disability was established fall 2009
2. UNICEF joined the Workgroup in early 2011
3. First draft module presented Nov. 2011 @ 11th WG meeting in Bermuda
4. April 2012: “Rome meeting”: revision and extension of the module
5. June 2012: “Technical Consultation on the Measurement of Child Disability meeting” hosted by UNICEF: revision of the module
6. October 2012: Revised version presented @ 12th WG meeting (Thailand)

Working on Child Functioning and Disability: progress and meetings (b)

7. Since September 2012: validation process in progress
 - Cognitive tests: India, USA, Belize, Oman, Montenegro.
 - Field tests: India, Cameroon, Haiti, Italy.
5. October 2013: Revised version presented @ 13th WG meeting (Jordan)
6. January-July 2014: new cognitive tests in USA
7. October 2014: Final version presented @ 14th WG meeting in Argentina.

Working on Child Functioning and Disability: progress and dissemination

Presentations:

- December 2012: UNICEF/WG webinar
(<http://www.childinfo.org/webinars.html>)
- February 2013: Side event during the 44th Meeting of the UN Statistical Commission in NY
- July 2013: “Sixth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities”
- September 2013: “Joint academic symposium UNICEF/Columbia University on the measurement and assessment of child disability in low- and middle-income countries”
- February 2014: Side event during the 45th Meeting of the UN Statistical Commission

Working on Child Functioning and Disability: Progress and Dissemination

Publications:

- UNICEF annual international report “The State of the World’s Children” 2013
- chapter for “International Measurement of Disability: Purpose, Method and Application. The Work of the Washington Group”, Ed. B. M. Altman, Springer (forthcoming)

The working group on Child Functioning and Disability

- Members are from across the world
- The task of the working group was to develop a set of questions to measure child disability to be used in population surveys to provide cross-nationally comparable data.
- The starting point was to agree on some principles to guide the further work:
 - *conceptual framework*
 - *purpose of the measurement*
 - *approach to the measurement*
 - *population reference*
 - *criteria for proposing questions*

The working group on Child Functioning and Disability

-The working group also agree to take into account:

- the WG work in the development of the short and the extended set of questions for adults - as well as ...

- studies already carried out on the development of child disability survey measures and national and international surveys on child disability.

and considered essential to:

- consult experts such as paediatricians, developmental psychologists, speech therapists etc.

- validate the module through cognitive and field tests, following WG procedures.

Guiding Principles for developing the Module ⁽¹⁾

Conceptual framework: The definition of disability adopted is the one set out in the ICF (WHO):

Disability “denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual (environmental and personal) factors.”

ICF-CY (WHO, 2007) as reference for selecting the relevant domains to be included in the module.

Guiding Principles for developing the Module ⁽²⁾

Purpose of measurement: to identify the sub-population of children and youth who are “at greater risk”, than similarly aged children in the general population, of experiencing limited social participation.

Approach to measurement: to measure “difficulties in functioning”. Functional difficulties are identified in the basic action and complex activities appropriate to the reference age and are culturally sensitive.

Population reference: 0-17 years old vs 2-17 years old

Guiding Principles for proposing the questions ⁽³⁾

- To avoid a medical approach and use the ICF bio-psycho-social model
- to select basic actions and complex activities that can identify the main types of functional limitations in children
- to formulate questions that are culturally relevant and able to collect comparable data cross-nationally
- to consider, where applicable, questions already tested including those of the WG short and extended sets
- to propose age-specific questions

Guiding Principles for proposing the questions (2)

- To propose questions and answer categories able to get the severity of the activities limitation in order to reflect disability continuum.
- Questions should be asked to parents or primary caregivers.
- Questions should include, when appropriate, the reference “Compared with children of the same age...” to standardize the expectations of the proxy-respondents by focusing attention on the functioning of their own child in relation to the child’s age.

Selection of appropriate and feasible domains:

Based on ICF-CY, literature review, analysis of health/disability surveys the following domains were selected to form a minimum set/survey instrument for international comparison:

Vision

Hearing

Walking

Communication

Learning

Playing

Relationships

Behaviour

Attention

Self-care

Emotion

Coping with change

Domains and number of questions by age class

DOMAINS	AGE CLASS	
	2-4 years	5-17 years
Vision	2	2
Hearing	2	2
Walking	2-3	2-3
Communication	2	2
Learning	1	1
Behaviour	1	1
Playing	1	-
Remembering	-	1
Attention	-	1
Relationships	-	1
Self-care	-	1
Emotion	-	2
Coping with change	-	1

Working on Child Functioning and Disability: Progress and Dissemination

Documentation: A manual for users of the Module is in progress.

It will provide guidance on all aspects of the implementation of the module, as well as in the analysis and dissemination.

The manual should be available at the end of 2014.

Detailed information will be provided during this session

Childhood disability: a new topic for WG and UNICEF collaboration

Development of another extended set of questions on child disability that will focus on environmental factors and school participation.

UNICEF is leading the work and has organized 2 meetings on “Measuring Environmental Factors and School Participation for Children with Disability”:

-11 June 2013 (with external experts)

-23 September 2013 (internal meeting)

Progress with this module will be presented during this session.