

The WG Workgroup on Child Functioning and Disability

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Working on Child Functioning and Disability: Background (1)

- UN Convention on the Rights of the Child (1989)
- UN Convention on the Rights of Persons with Disabilities (2006)
- Disability and Health for Children and Youth (ICF-CY) (WHO, 2007)

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

Working on Child Functioning and Disability: Background (2)

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. 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**

Challenges:

- Disability in children is far more difficult to define for children:
 - 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

Child Functioning and Disability module

Goal of the workgroup:

Develop a set of questions on child functioning and disability

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

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 Conventions

Child Functioning and Disability module

The **Module** measures “difficulties in functioning”.

Functional difficulties are identified in the basic action appropriate to the reference age and culturally sensitive

The aim of the Module is **to provide cross-national 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.).

Select 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:

Vision

Hearing

Walking

Communication

Learning

Playing

Relationships

Behaviour

Attention

Self-care

Emotion

Coping with change

A set of questions was drafted following these guidelines:

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

Questions are asked to parents or primary caregivers.

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

1. WG 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: 12th WG meeting: presentation of the new module
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Working on Child Functioning and Disability: progress and meetings (b)

7. Since September 2012: validation process

According with the WG's validation procedures the module on child functioning and disability has been tested through both cognitive and field tests

- Cognitive tests: India, USA, Belize, **Oman**, Montenegro
- Field tests: India, Cameroon, Haiti, **Italy**

8. June & September 2013: one-day small meetings to review CT preliminary results

Working on Child Functioning and Disability: progress and dissemination

Documentation: A manual for Module users 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 in 2014.

Presentations:

- December 2012: UNICEF/WG webinar (<http://www.childinfo.org/webinars.html>)
 - February 2013: Side event during the 44th 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”.
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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)
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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)

A draft set of questions should be produce by the end of 2013.
