The WG Workgroup on Child Functioning and Disability

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Working on Child Functioning and Disability: group members

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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.
Goals of the workgroup

Develop and test a set of questions on child functioning and disability

Primary purpose: to identify the sub-population of children and youth (aged 0-17 years) who are “at greater risk” than the children of the same age of experiencing limited social participation.

The set of questions is intended to be used as components of national population surveys or as supplements to surveys on specific topics of interest (health, education, etc.) with the aim to provide cross-national comparable data.
Working on Child Functioning and Disability: meetings

- end of 2009 the workgroup on Child Functioning and Disability was established
- in early 2011, UNICEF joined the workgroup
- Nov. 2011: 11th WG meeting in Bermuda: first draft of the module
- April 2012: “Rome meeting”: revision and extension of the module
- June 2012: “Technical Consultation on the Measurement of Child Disability meeting” by UNICEF: revision of the module
- October 2012: 12th WG meeting: presentation of the new module

Since September 2012: validation process (cognitive and field tests)
Working on Child Functioning and Disability

The group took into account:

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

- 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.
Select appropriate and feasible domains:

The ICF-CY is the conceptual framework used for the selection of the relevant domains to be included in the module.

All the ICF-CY check list have been included in one, adding the age group in which the domain is applicable, then all the surveys on child disability were mapped onto the ICF-CY Check list to see which domains had been covered in at least one of the surveys.

The ICF-CY Check List has been sent to all members of the group asking them to rate each ICF-CY domain on 6 criteria (Relevance, Accuracy, Reliability, Coherence and comparability, Clarity, Validity) for the purpose of creating a WG set of questions for children.
Module on child functioning and disability

Based on the results of this rating exercise, the ICF domains already covered in surveys and literature the following minimum set of domains was selected:

Vision  Hearing  Walking  Communication
Learning  Playing  Relationship

*and after the 11th WG meeting*

Self-care  Emotion  Behaviour  Attention
Coping with change
Guidelines in proposing the questions (1)

• avoid a medical approach
• use the ICF bio-psycho-social model
• use, when appropriate, questions already tested and adopted by the WG;
• include the reference “Compared with children of the same age...”
• consider age specificity when constructing questions
• response options to reflect disability continuum.
Guidelines in proposing the questions (2)

Age range considered for the set of questions: 2-17 years of age.

Questions will be asked of parents or primary caregivers.

The aim of the questions is to provide comparable data cross-nationally.
Revision of the questions (1)

- A first draft was presented at the 11th WG meeting in Bermuda

Main outputs and new challenges:
- to evaluate the feasibility of measure disability for children under 2
- to review the age groups for specific questions
- to review questions on Learning: too focused on “education”
- to add new domains (emotion, psychological functioning)
- to collaborate with UNICEF on the development of the module
- to further consult developmental experts regarding the activities selected and the appropriate age range.
Revision of the questions (2)

To address the issues emerged in the WG meeting it has been held a “brainstorming meeting” in Rome April 2012, where it was decided:

- population age reference for the module: 2 up to 17 years old.
- Despite the recognized importance of early detection of children with functional difficulties, to capture children under 2 years of age through surveys may lead to large proportions of false positive cases. In this age range the development process is very subjective and culturally influenced, and a developmental delay is not necessarily a sign of functional limitation.
Revision of the questions (3)

To harmonize the age groups questions: **2-4 years and 5-17 years classes** were considered reasonable for all the set of questions.

A strictly age-specific activities approach would provide more accurately information on developmental delay but at the same time it will greatly complicate the questionnaire requiring numerous skip patterns in all its part.

A questionnaire so designed may become challenging and quite demanding for both the interviewers and the respondents.

Exception for learning and playing.
Revision of the questions (4)

- To change the questions on learning.
- To add new domains: questions have been developed on Self-care, Emotion, Behaviour, Attention, Coping with change

-To participate to the “Technical Consultation on the Measurement of Child Disability meeting” organized by UNICEF (New York, June) for consultation with experts (disability surveys, paediatricians, developmental psychologists, speech therapists etc.).

- Several aspects were addressed to improve the reliability of the module in measuring child disability in the international context.
Validation process for the questions

☐ According with the WG’s validation procedures the module on child functioning and disability will be tested through both cognitive and field tests

☐ with the participation of some countries already involved in testing the short and/or the extended WG set and other countries involved in the MCIS.

☐ Cognitive tests are in progress in India and Usa; Belize and Kenya maybe start soon.