

# The WG Workgroup on Child Functioning and Disability

---

Roberta Crialesi

Italian Institute of Statistics Istat/  
Washington Group on Disability Statistics

**12th WG meeting, Bangkok, 24 October 2012**

# Working on Child Functioning and Disability: group members

---

Roberta Crialesi, Elena De Palma, Alessandra Battisti, ISTAT- **Italy**

Howard Meltzer University of Leicester – **UK**

Mitch Loeb (CDC) **USA**

Claudia Cappa **UNICEF**

Andrew MacKenzie, Krista Kowalchuk Statistics-**Canada**

Hasheem Mannan (Centre for Global Health, Trinity College Dublin)  
**Ireland**

Daniel Mont, (University College London) **UK**

Julie Dawson Weeks (CDC) **USA**

Helen Nviiri (Uganda Bureau of Statistics) **Uganda**

Paula Monina Collado (National Statistics Office) **Philippines**

Indumathie Bandara (Department of Census and Statistics) **Sri Lanka**

Tserenkhand Bideriya (National Statistical Office) **Mongolia**

Obert Manyame (Central Statistics Office) **Zimbabwe**

Matthew Montgomery (Australian Bureau of Statistics) **Australia**

# 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: 11<sup>th</sup> 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: 12<sup>th</sup> 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 11<sup>th</sup> 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 <sup>(2)</sup>

---

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 11thWG 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.