The WG/UNICEF Module on Child Functioning



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

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

- different priority given to *children* and to *disability* in the political agenda at national level
- different local resources available for data collection at national level
- cultural factors (such as differences in values and attitudes towards individuals with disabilities) influence reporting child disability in the surveys
- 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.

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 nonaccommodating 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

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)

* Comparable WG SS questions
** Comparable WG ES questions

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)