Development of a survey questionnaire module on child functioning and disability

Washington Group on Disability Statistics

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Background

The Convention on the Rights of the Child, adopted in 1989 (UNICEF, 1989), included the first explicit provision relating to the rights of children with disabilities. It included a prohibition against discrimination on the grounds of disability (art. 2), and obligations to provide services for children with disabilities, in order to enable them to achieve the fullest possible social integration (art. 23).

The more recent Convention on the Rights of Persons with Disabilities (UN, 2006), adopted in 2006, further strengthened the rights of children with disabilities with a dedicated article on children (art. 7). This outlined the obligation on States to ensure the realization of all rights for children with disabilities on an equal basis with other children, to promote their best interests, and to ensure their right to be heard and taken seriously. It incorporates, within its general principles (art. 3), respect for the evolving capacities of children with disabilities and their right to preserve their identities, and introduces a general obligation (art. 4) to consult with children, through their representative organizations, when developing relevant legislation and policies.

These Conventions focus on the disparities faced by children with disabilities and call for improvements in their access to services, and in their participation in all aspects of life. In order to achieve these goals, there is a need for improved data collection internationally. The current lack of accurate data impedes the development, implementation and evaluation of policies and programmes that would improve the lives of children with disabilities.

The UN Convention on the Rights of Persons with Disabilities encourages States to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention (art. 31).

The limits of the data available and the importance of improving statistical information on disability in order to develop internationally comparable indicators for policy purposes has been also stressed by the UN General Assembly 2011 - special section on “Status of the Convention on Rights of the Child” and in the World Disability Report 2011 (WHO, 2011).

The Washington Group on Disability Statistics (WG) is a United Nations (UN) sponsored City Group commissioned in 2001 to improve the quality and international comparability of disability measures. The main purpose of the WG is the promotion and co-ordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability which is comparable throughout the world. More specifically, the Washington Group aims to guide the development of a short set of disability measures, suitable for use in censuses, sample-based national surveys, or other statistical formats, for the primary purpose of informing policy on equalization of opportunities for people with disabilities. A second priority is to recommend one or more extended sets of survey items to measure disability, or guidelines for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items are intended to be related to the short set of disability measures. The World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) has been selected as the conceptual framework for the development of the sets.
Due to the limited space available in Censuses and surveys, the WG selected questions that follow the ICF framework of disability and use a functional approach to examining disability. The functional approach was selected for a variety of reasons that are only summarized in this paper but can be found in detail in Madans et al (2004). In short, the functional approach to disability measurement indicates areas of daily life where respondents are experiencing difficulty functioning in their environments. Awareness of these functional difficulties can feed directly into the development and implementation of new policies, programs and services for people with disabilities because it provides direct information on the type of difficulties people are experiencing, allowing them to be addressed. Strictly medical assessments of the bodies or minds of people with disabilities offer little information that can be used directly to improve functional abilities in the broader social context. See Madans et al (2004) for more information.

The WG has already developed, and endorsed a short set of questions, to be used on census and surveys, that comprised questions on six core functional domains: seeing, hearing, walking, cognition, self-care and communication. The group has also developed and endorsed an extended set of functioning questions to be used as components of population surveys, as supplements to surveys or as the core of a disability survey that expand on the short set; this set includes the following functional domains: vision, hearing, mobility, cognition, self-care, communication, upper body, affect (anxiety & depression), pain and fatigue.

Both the short and extended sets of questions on functioning have undergone several rounds of cognitive and field testing in several countries with training and technical assistance by the Washington Group. Detailed information on the testing is available from the following sources: Miller et al (2011); http://www.cdc.gov/nchs/washington_group/wg_meeting9.htm; and http://www.unescap.org/stat/disability/analysis/.

The short set of questions developed by the WG, was intended primarily for the adult population, and though certain questions may be suitable for some child/youth sub-populations, the set was not developed with this group in mind. The WG has recognized the need for a set of questions on child functioning and disability that would produce internationally comparable data. At the 10th WG meeting (2009) a sub-group was established that would focus on the development of a set of questions intended to measure child (and youth) disability in surveys. UNICEF, the United Nations Children’s Fund has been working in the area of child disability and measurement for several years through their Multiple Indicator Cluster Surveys (MICS). In February 2011 UNICEF expressed interest in the work of the WG and subsequently joined the workgroup on child functioning and disability.

**Some guiding principles**
The Child Disability Workgroup agreed on some guiding principles for the work to be carried out:

1) The primary purpose of the questions is to identify the sub-population of children that are “at greater risk” than the children of the same age of experiencing limited social participation.

2) The definition of disability adopted is the one set out in the World Health Organization International Classification of Functioning, Disability, and Health (ICF): Disability is a complex process that “denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual (environmental and personal) factors”.

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3) The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), (WHO, 2007), is the conceptual framework to be used for the selection of the relevant domains to produce a set of questions that is going to be current, relevant and sustainable.

4) 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.

5) The distribution of types of disability are different for children compared with adults, as reported in publications from studies at the national and international level. In adults the major problems are mobility, sensory, and personal care - especially with advancing years. In children the main disabilities are related to intellectual functioning, affect and behaviour.

6) The work also takes into account the work of the WG in the development of the short and the extended set of questions for adults. In addition, there are several studies, and national and international surveys that are taken into account in proposing this new set of questions.

7) The population reference age for the new set of questions is 0-17 years, as stated in the ICF-CY. The workgroup is however aware that it may not be feasible to capture disabilities among children under 2 years of age through population surveys due to the nature of the development process for children of this age. A developmental delay at this age may not necessarily be indicative of functional limitation. Furthermore, children are constantly developing and in transition - from infancy to childhood, from childhood to adolescence and from adolescence to adulthood. For this reason the selection of the basic activity could change from one stage of life to another as well as the wording should be adapted to each specific age considered.

8) Questions are asked of parents or primary caregivers although they may not accurately represent the experience of the child as some studies have shown (Chamie M., 1994, O Dickinson HO et al, 2007). Frequently, children and parents have a different perception of reality, nevertheless, sets of questions addressed directly to the children are rare (i.e. Activities Scale for Kids, see, Young NL et al, 2000) and information provided by children usually supplement that given by parents/caregivers.

9) The aim of the questions is to provide comparable data cross-nationally. It is important to consider that the questions are designed to identify persons with a similar type and level of limitations in basic activity functioning regardless of nationality or culture. Therefore the questions should refer to basic functional actions and “life situations” ideally applicable to children in different countries.

10) For reference and to focus the respondent on the functioning of their own child in reference to that child’s cohort, each question is prefaced with the clause: “Compared with children of the same age…”.

11) Disability can be conceptualized on a continuum from minor difficulties in functioning to major impacts on a person’s life, therefore the answer categories are designed to reflect this continuum with the ability to determine appropriate cut-offs based on the requirements for the disability data collection.

12) Consultation with other experts, not only survey statisticians but also paediatricians, developmental psychologists, speech therapists etc. is sought to support the work.
13) The set of questions is validated through cognitive and field testing, following established WG procedure.

**Work accomplished**
The first step in producing a set of questions to measure child and youth functioning and disability able to provide comparable data cross-nationally, was to select appropriate and feasible ICF domains. To this end, the working group collected and analysed documentation relating to the measurement of childhood disability, especially questionnaires of surveys on children already conducted in several countries. Based on this assessment, the following first set of domains was selected: seeing, hearing, mobility, communication/comprehension, learning, relationships, and playing.

The second step was to produce a first draft of the set of questions/wording. With this goal, a detailed review of all the questions already used in national or international surveys as well as in other tests on the selected domains was carried out. Therefore a set of questions was created, following the guidelines below:

- to avoid questions with a medical approach
- to use the bio-psycho-social model to produce a set of questions in line with the ICF;
- to use, when appropriate, the questions already tested and adopted by the WG;
- to include as reference “Compared with children of the same age…”, exception for questions on seeing and hearing.
- to propose, when available, questions already age-specific while in other cases to adjust question for specific ages.
- to change the wording of the questions and the answer categories to fit WG questions design in order to harmonize the set of questions and to obtain a graduation of difficulty and not only the presence / absence of the difficulty.

This set of questions was presented and discussed at the 11th WG meeting in Bermuda (November 2011). An important outcome of the meeting was a formal collaboration between the WG and UNICEF to work on the further development of the set of questions on child disability.

The third step was a revision of the question set. Based on the collaboration with UNICEF, a “brainstorming meeting” was held in April 2012 in Rome. Several methodological issues were addressed (i.e. population age reference, age group disaggregation, add new domains, simplify and harmonize the questions as well as the flow of the module) and a new set of questions was produced.

It was decided that despite the recognized importance of early detection of children with functional difficulties and at risk of participation restrictions and the subsequent need for early intervention, to capture children under 2 years of age through surveys designed for research purposes would be extremely challenging. Among infants and children 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. The inclusion of children under 2 years of age may lead to large proportions of false positive cases due to the nature of the development process for children of this age. The population age reference for the set of questions is 2-17 years.

One way to more accurately obtain information on developmental delay is to include questions on specific activities that apply to limited age ranges. This approach would greatly complicate the questionnaire, and require numerous skip patterns. A questionnaire so designed may become
challenging and quite demanding for the interviewers. Therefore, questions were developed that would be appropriate for larger age ranges. Generally the age groups considered are 2-4 years and 5-17 years, with few exceptions (see the Module for details). For reference, each question is prefaced with the clause: “Compared with children of the same age…”

Furthermore, it was decided to:
- add questions on self-care as well as for emotional/psychological functioning (specifically emotions, behaviour, attention and coping with change).
- add the following preamble to the set of questions: The next questions ask about difficulties your child may have in doing certain activities...
- validate the proposal by the UNICEF meeting (New York, June, 2012) and by cognitive and field testing in several countries across the world.

The new set of questions was presented during the “Technical Consultation on the Measurement of Child Disability meeting” organized in June 2012 in New York by UNICEF. At this meeting the Module was presented and discussed among a wide audience of experts, not only in the field of disability surveys, but also in child development (paediatricians, developmental psychologists, speech therapists etc.). Several aspects were discussed during the consultation to improve the reliability of the module in measuring child disability in the international context.

The fourth step is the validation process. 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 MICS. Cognitive tests are in progress in USA and in India and other countries have indicated that they are willing to conduct tests.
References


