

Module on Child Functioning and Disability

Washington Group on Disability Statistics / UNICEF

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 also been 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 co-operation 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. To that end the WG has developed 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. The short set includes six core functional domains: seeing, hearing, walking, cognition, self-care and communication. The WG has also developed an extended set of survey items on functioning to be used as components of population surveys or as supplements to specialty surveys. This extended set of survey items expands on the short set of disability measures, including additional domains of functioning (upper body functioning, affect, pain, and fatigue) and more information per domain (for example, functioning with and without assistance).

The WG chose to use the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) as the conceptual framework for the development of question modules. Furthermore, the WG selected questions that reflect a functional

approach to operationalizing 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) (http://www.cdc.gov/nchs/data/washington_group/WG_purpose_paper.pdf). In short, the WG approach to disability measurement identifies basic activity or functioning domains where respondents may experience difficulty functioning in their environments.

The WG short set was adopted in 2006 and the extended set on functioning was adopted in 2009. Both the short and extended sets of questions on functioning have undergone to 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 has supported over the years the collection of data on this topic through the Multiple Indicator Cluster Survey (MICS). MICS is a household survey programme developed by UNICEF to assist countries in filling data gaps for monitoring the situation of children and women through statistically sound, internationally comparable estimates of socioeconomic and health indicators. Since the initiation of the MICS in 1995, more than 240 surveys have been implemented in more than 100 low- and middle-income countries. Data on child disability were first collected during the second round of MICS in 2000. Since then, more 50 surveys have gathered information on disability, making MICS the largest source of internationally comparable data on children with disabilities for low- and middle-income countries. In 2011 UNICEF decided to revise the disability module used in the MICS surveys and collaborate with the Washington Group for a development of a joint module.

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 children with functional difficulties. These functional difficulties may place children at risk of experiencing limited participation in an unaccommodating environment.
- 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”.
- 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, where appropriate, questions are 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. In a second stage of the work, questions on the following aspects were also developed: emotions, behaviour, attention and coping with change.

The **second step**: developing 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, where appropriate and as reference “*Compared with children of the same age...*”.
- 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**: 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 in a way 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). Furthermore, to standardize the expectations of the proxy-respondents by focusing attention on the functioning of their own child in relation to the child’s age, the questions should begin with the clause: “*Compared with children of the same age...*”, where it is appropriate.

Moreover, 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: the validation process.

Following established WG validation procedures, the module on child functioning and disability is undergoing cognitive and field testing. During 2012 and 2013 cognitive tests have been conducted in the following countries: India, Belize, Oman, Montenegro, and USA.

The results of cognitive testing were presented in Amman at the 13th WG meeting; and a revised version of the Module on Child Functioning and Disability was prepared based on these findings as well as comments from the participants of the 13th WG meeting. A final report of the combined results of cognitive testing has been prepared.

The revised version of the module will be cognitively tested in January 2014 in USA in preparation for field testing. In Amman, results of some ad hoc fields testing carried out in Cameroon by the London School of Hygiene and Tropical Medicine, and Italy by the Italian Institute of Statistics were presented.

Plans for field testing of the final version of the module were discussed, with testing beginning in 2014 and preliminary results presented to the 14th meeting of the WG in Buenos Aries in October 2014.

The fifth step: establishing the analytic properties of the module.

The field test of the module included a few follow-up probe questions for certain domains of functioning. Probe questions were developed either from thematic response patterns that emerged during the cognitive testing of the module or were designed to elicit further information on the respondent’s reason for their choice of response.

The addition of follow-up probe questions to the field test helps in our understanding of the properties of certain questions and aids in establishing thresholds for inclusion into the group of children identified as having functional difficulties.

Upon completion of the field testing, analysis of field test data will provide valuable information that will support the understanding of specific domains of functioning and the overall module.

Supporting documentation

Similar to the other disability measures recommended by the WG, the “Module on Child Functioning and Disability” will be accompanied by descriptions of its technical properties, as well as methodological guidance for its implementation. To that end, a manual is being prepared that will provide guidance on all aspects of the implementation of the module, as well as in the analysis and dissemination. It will include the following main topics:

- How the module was developed, and rationale of each question
- Results of the cognitive and field tests
- How this module differs from the WG module for adults

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- How/where this module can be used (new/ongoing surveys, etc.)
- Instructions on translations
- Sampling issues
- Data processing and tabulation plan
- Template for reporting and guidelines for data analysis and presentation
- Instruction of interviewers and related training material

The manual should be available in mid-2015.

Dissemination of the work carried out by the group

It is important that information about the work undertaken with UNICEF on the development of the module on child functioning and disability is widely disseminated. Several initiatives have undertaken in this regard:

- In December 2012, UNICEF and the WG organized a webinar “UNICEF/Washington Group on Disability Statistics Module on Child Functioning and Disability” to inform and up-date interested parties of the work in progress.
- During the 44th meeting of the UN Statistical Commission in New York a side event was organized: “UNICEF/Washington Group on Disability Statistics Module on Child Functioning and Disability” (28 February 2013).
- Presentations at: the “Sixth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities” (July 2013), and at the “Joint Academic Symposium UNICEF/Columbia University on the measurement and assessment of child disability in low- and middle-income countries” (September 2013).
- Furthermore, on 30 May 2013, UNICEF released its annual report “The State of the World’s Children”. The 2013 edition of the report focused on Children with Disabilities and mentioned the work done on the development of the UNICEF/WG module on child functioning and disability.
- During the 45th meeting of the UN Statistical Commission in New York a side event took place to present an up-date of joint WG/UNICEF activities in the area of child disability measurement (6 March 2014).
- Finally, a new book about the work of the Washington Group on Disability Statistics is in progress. Included in this edition will be a chapter on the work carried out by the WG/UNICEF collaboration: “International Measurement of Disability: Purpose, Method and Application. The Work of the Washington Group”, Ed. B.M. Altman, Springer (forthcoming).

Environment and school participation: A new topic for collaboration between WG and UNICEF

In June 2013 the Washington Group and UNICEF commenced work on the development of another survey module that will focus on environmental factors that affect school participation. To that end, a brainstorming meeting the Measurement of Facilitators and Barriers to School Participation for Children with Disability was organized by UNICEF n aimed at understanding the different aspects related to environment, participation and disability within the context of school participation with the goal of identifying a conceptual framework that can guide the development of questions. Based on the discussions, a framework was drafted and questions will be developed taking into account four main domains of barriers to school participation (attitudes, getting to school, accessibility within the school, and affordability). A desk review of questions used in surveys to collect data on access to school, environmental factors and participation has been conducted by UNICEF and a

draft set of questions is under development. The draft questions were presented at the 14th meeting of the WG in October 2014 and will be cognitively tested in early 2015.

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