

UNICEF/ Washington Group on Disability Statistics Child Functioning Module¹

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

¹ For information on UNICEF's work on child disability data, please contact: Claudia Cappa, Data and Analytics Section, UNICEF NY, ccappa@unicef.org.



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). In short, the WG approach to disability measurement identifies basic activity or functional 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 several rounds of cognitive and field testing in several countries, with training and technical assistance provided by the Washington Group. Detailed information on the testing is available in Miller et al (2011).

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.

Over the years UNICEF has supported 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 than 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 the development of a joint module.

Guiding principles

The Working Group on Child Disability 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 other main aim of the questions is to provide cross-nationally comparable data. It is important to consider that the questions are designed to identify children with similar types of functional difficulties in basic activity, regardless of nationality or culture. Therefore the questions should refer to basic functional actions applicable to children in different countries and life situations.

- 3) The definition of disability adopted is as per the World Health Organization International Classification of Functioning, Disability, and Health (ICF). Disability is understood as 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”.
- 4) The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), (WHO, 2007), is the conceptual framework that guided the selection of relevant domains within which a set of current, relevant, and sustainable questions on child functioning was developed.
- 5) The development of the child functioning questions built upon the WG’s work on the short and extended sets of questions for adults. Findings from several studies and national and international surveys were also taken into account.
- 6) Consultation with other experts, including survey statisticians, paediatricians, developmental psychologists, speech therapists, etc. was sought to support the work.
- 7) The population reference age for the child functioning questions is 0-17 years, as per ICF-CY recommendations. However, capturing disabilities among children under 2 years of age through population surveys is challenging. Due to the transitional nature of the development process for young children, a developmental delay at this age is not necessarily indicative of functional limitations. Therefore, trying to assess difficulties in functioning may yield misleading results for this age group.
- 8) Questions on child functioning are asked of parents or primary caregivers although they may not always accurately represent the experience of the child (Chamie M., 1994, O Dickinson HO et al, 2007). While it is understood that children and parents have different perceptions of reality, questions addressed directly to children are rare (i.e. Activities Scale for Kids, see, Young NL et al, 2000), and information provided by children usually supplements information provided by parents/caregivers.
- 9) For reference, and to focus the respondent on the functioning of their own child in comparison to that child’s cohort, where appropriate, questions are prefaced with the statement: “Compared with children of the same age...”
- 10) Disability can be conceptualized on a continuum from minor difficulties in functioning to major impacts on a person’s life. Therefore answer categories are designed to reflect this continuum, with cut-offs that can be determined based on the requirements of disability data collection efforts.
- 11) The set of questions is validated through cognitive and field testing, following established WG procedure.
- 12) National and international studies have found that the distribution of types of disability is different for children and adults. Adults face the most difficulty in mobility, sensory, and personal care - especially with advancing years. For children, the most prevalent disabilities are related to intellectual functioning, affect and behaviour.
- 13) The set of child functioning questions can be used as a component of national population surveys or as a supplement to surveys on specific topics: health, education, etc.

Work accomplished

The **first step** in producing a set of questions to measure child and youth functioning and disability to provide cross-nationally comparable data, 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 from surveys already conducted in several countries. Based on this assessment, the 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: self-care, fine motor, remembering, emotions, controlling behaviour, attention and concentrating, 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 biopsychosocial 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 question 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, addition of new domains, simplification and harmonization of 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. Therefore it was agreed that the population age reference for the set of child functioning 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. 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 and on 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 Child Functioning module underwent cognitive and field testing. During 2012 and 2013 cognitive tests were conducted in the following countries: India, Belize, Oman, Montenegro, and the USA.

The results of cognitive testing were presented in Amman at the 13th WG meeting in October 2013, and a revised version of the Child Functioning Module was prepared based on these findings as well as on comments from the participants of the 13th WG meeting.

The revised version of the module was cognitively tested in January 2014 in the USA, and findings were presented at the 14th WG meeting in Buenos Aires in October 2014.

Field testing on the module began in Samoa in July 2014 by the Samoa Bureau of Statistics.² The Child Functioning module was included in the Samoa Demographic and Health Survey 2014. Preliminary findings, presented at the 15th WG meeting in Copenhagen, highlighted the need for further adjustments to the questions. The revised module was cognitively tested for the third time in the USA in August 2014, with revisions finalized in preparation for further field testing.

² Ad hoc independent fields testing on a subset of draft questions was carried out in India and Cameroon by the London School of Hygiene and Tropical Medicine in 2013/2014, and in Italy in 2012/2013 by the Italian Institute of Statistics.

The Directorate of Statistics and Censuses in El Salvador field tested the module in October 2015, as part of a National Survey on Disability, and the Statistical Office of the Republic of Serbia field tested it in February 2016. Findings from the two field tests resulted in further, minor, changes being made to some questions, with the revised version of the module undergoing further cognitive testing in the USA in February 2016, India in March 2016, and Jamaica in April 2016.

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

The field tests 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 helped understanding the properties of certain questions and establishing thresholds for inclusion into the group of children identified as having functional difficulties. In-depth data analyses were also conducted to explore the psychometric properties of the module.

Supporting documentation

Similar to the other disability measures recommended by the WG, the module on child functioning is accompanied by interviewer instructions. A description of its technical properties, as well as methodological guidance for its implementation will follow in early 2017. 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
- 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

Dissemination of the work carried out by the group

It is important that information about the work undertaken with UNICEF and the WG on the development of the module on child functioning is widely disseminated. Several initiatives have been 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).
- A country workshop was hosted in Tunisia in February 2015, with representation from the national statistics office, government staff, and disabled peoples’ organizations. The workshop focused on the measurement of child disability, and discussed theoretical and conceptual issues, as well as considerations for the planning, design and implementation of child disability data collection efforts.
- During the 46th 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 (5 March 2015).
- The first regional workshop for the CEE/CIS region was held in Geneva in July 2015, with 112 participants from 26 countries, including 21 national statistics offices, and representatives from various ministries, UNICEF country offices, and civil society organizations.
- During the 47th meeting of the UN Statistical Commission in New York, a side-event-Disability Statistics: A Key to Inclusion-was organized, where the Child Functioning module was presented (9 March 2016).
- The first workshop for disabled peoples’ organizations was held in New York in June 2016, with approximately 30 participants from international DPOs in attendance (17-18 June 2016).
- A regional workshop for the LAC region was held in New York in October 2016, with 90 participants from 27 countries, as well as a delegation from the LAC regional office. In addition to the delegations from LAC, also in attendance were delegations from Thailand, Vietnam, and the Pacific Islands. Participants included representatives from national statistics offices, ministries, disabled people’s organizations, and UNICEF country offices. Additional workshops are planned for 2017 for representatives from the African regions, MENA, and ROSA.
- 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).

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Members of the WG Working Group on Child Disability:

The workgroup is currently headed by Mitchell Loeb (CDC – USA) and includes:

Claudia Cappa (UNICEF)

Roberta Cialesi, Elena De Palma, Alessandra Battisti (ISTAT– Italy)

Helen Nviiri (Bureau of Statistics – Uganda)

Sawsan Dawood Mahmood (Ministry of National Economy – Oman)

Sumaya Ahmed (Sudan Central Bureau of Statistics – Sudan)

Olimpio Zvale (Instituto Nacional de Estatistica – Mozambique)



Xiaoying Zheng (Institute of Population Research – China)

M'Banan Hippolyte Kone (Institut National de la Statistique – Cote d'Ivoire)

Souradji Fankeba (General Directorate of Statistics – Togo)

Tomislav Benjak (Croatian Institute of Public Health – Croatia)

Associate experts:

Hasheem Mannan (The University of Melbourne, Nossal Institute for Global Health - Australia)

Daniel Mont (University College London – UK)

Islay Mactaggart (London School of Hygiene and Tropical Medicine – UK)

Marieta Visser (Free State University – Republic of South Africa)

