



## Advances in the measurement of Child functioning and disability

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### Abstract

In 2009, the Washington Group on Disability Statistics (WG) began work on the development of a set of questions on child disability for use in surveys. This coincided with the plans of UNICEF to revise the existing data collection module used in the Multiple Indicator Cluster Survey (MICS) program. The need for more information on childhood disability has been widely and repeatedly emphasized in national and international arena as the little data available nationally are not comparable cross-nationally. This lack of data seriously impedes the development, implementation and evaluation of disability policies for children that should sustain the respect of human rights by the UN Conventions. Furthermore, the International Classification of Functioning, Disability and Health presents a new definition of disability that should find an implementation also in survey measures. This paper presents the work carried out by the Washington Group on Disability Statistics and UNICEF in developing a “Child Functioning and Disability Module” - for children aged 2-17 years - to be used in population surveys to provide cross-nationally comparable data on childhood disability.

**Keywords:** child disability, cognitive testing, question design & evaluation

### 1. Introduction

The children’s fundamental rights have been fully recognized, at international level, back in 1989 by the UN Convention on the Rights of the Child (UN 1989); these rights are founded on respect for the dignity and worth of each child without distinction of any kind (health, sex, age, race etc.). The attention to create policies to support the implementation of these rights for children with disability was reinforced by the UN Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006).

The Convention also requires to the States parties to strengthen the collection of data and information for monitoring the rights of persons with disabilities. The need to improve data collection on disability across the world has been stressed also by the “World Report on Disability” (WHO and World Bank 2011) and, in particular on childhood disability, by the United Nations Children’s Fund annual report (UNICEF 2013).

Indeed, different factors undermine the cross-national comparability of data on disability. Countries collect these data in different ways (administrative records or registers, census, population survey). Since several definitions and models of disability have been developed along the years (Altman 2001), many approaches for measuring disability are used in the surveys, leading to disparate prevalence rates among countries (Mont 2007; Barbotte et al. 2001; Loeb 2013; WHO and World Bank 2011; UNICEF 2013). This is even more relevant regarding childhood disability measures.

The Washington Group on Disability Statistics (WG)<sup>1</sup> is a United Nations (UN) sponsored City Group, commissioned in 2001 to improve the quality and international comparability of disability measurement. It has been aware, since its formation, that the childhood disability measurement was also a major issue to be addressed. The WG has developed so far *a short set* of disability measures (six questions), suitable for use in censuses, sample-based national surveys, or other statistical formats, as well as *an extended set* of survey items on functioning to be used as components of population surveys or as supplements to specialty surveys. Those survey instruments have been produced, using the

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<sup>1</sup> For more information [http://www.cdc.gov/nchs/washington\\_group.htm](http://www.cdc.gov/nchs/washington_group.htm).

International Classification of Functioning, Disability and Health (ICF) as a conceptual framework, for the primary purpose of informing policy on equalization of opportunities for people with disabilities. The UNICEF plays an important role in supporting disability child data collection in low/middle-income countries; in particular, since 2000 the “Ten Questions Screen (TQ)”<sup>2</sup> has been included in the Multiple Indicator Cluster Surveys” (MICS)<sup>3</sup>. Nevertheless, the “TQ” design reflects disability as it was understood and measured before the “International Classification of Functioning, Disability and Health” (ICF) was published. In 2011, therefore, UNICEF decided to develop a new survey measure that could better reflect the current thinking about disability.

## 2. The WG-UNICEF Module and its development

At the end of 2009, the Washington Group has formed an ad hoc working group with the task to develop a set of survey questions specific on child disability and, by sharing the same objective, a formal collaboration with UNICEF was established in 2011.

One of the initial challenges was to develop a common definition of disability. The “International Classification of Functioning, Disability and Health” (ICF, WHO 2001) provides a useful model, by taking into account the social and contextual aspects of disability; it goes beyond an exclusively medical or biological dysfunctional approach and recognizes the impact of the environment on the person's functioning. The ICF provides a unified and standard language and framework for understanding disability, nevertheless, to translate the ICF concepts into a new operational definition of disability in surveys is not a straightforward task and requires the development of tools that measure disability, thus, as a result of the interaction between the person's health and their life context.

The Module on Child Functioning and Disability has been built following some guiding principles - based on literature/survey reviews, experts consultation and progress in the task- in order to insure that when used, the set of questions will yield valid, reliable and internationally comparable results.

- The *definition of disability* adopted is as stipulated 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” (WHO 2001, page 213).
- The *conceptual framework* is the International Classification of Functioning, Disability and Health for Children and Youth (WHO 2007) because it provides a common language and standard to classify the components of functioning and disability in children. It is therefore used for selecting relevant domains to develop a set of questions that is going to be current, relevant and sustainable.
- The *primary purpose of the module* is to identify the sub-population of children and youth “at greater risk” than the children of the same age of experiencing limited social participation. A major reason for this choice is the importance of the issue of social participation and equal rights from a policy perspective as illustrated in the UN Conventions.
- The *aim of the module* is to provide comparable data cross-nationally consequently the questions are designed to identify children with a similar type and level of functional difficulties regardless of nationality or culture, focusing on mainly on basic action that are appropriate to the reference age and not influenced by cultural and contextual factors.
- The *module is foreseen to be used* as a component of national population surveys or as a supplement to surveys on specific topics of interest, such as health, education, etc. For this reason a minimum set of domains and questions are identified as a balance between the information needs and the feasibility to be actually implemented, especially in developing countries where economic resources for surveys are limited.

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<sup>2</sup> The “TQ” is a validated screening tool used in interviewing the primary caregivers of children aged 2-9 years; it requires follow-up medical and developmental assessment. It contains questions on congenital and developmental disabilities, including seizures, speech, cognitive, motor, vision and hearing disabilities.

<sup>3</sup> For more information: [http://www.unicef.org/statistics/index\\_24302.html](http://www.unicef.org/statistics/index_24302.html)

- *The population target age is 2-17 years.* Initially, children under 2 were also included due to the importance of early detection and intervention. However, identifying these children in a household survey is extremely challenging as the development of infants and toddlers is very variable, subjective and culturally influenced and a developmental delay in this age is not necessarily a sign of functional limitation. The inclusion of children less than 2 years of age would likely lead to inconsistent and difficult to interpret results.
- *The age-group desegregation for the module is 2-4 and 5-17 years.* Indeed, considering that the target population is constantly developing, it was initially decided to use questions referred to specific activities that apply only to limited age ranges, in order to obtain more precise information on functional difficulties in children. Nevertheless, this approach would complicate the questionnaire as required numerous skips patterns and could difficult to administer accurately. For that reason, a balance was sought between simplicity and accuracy of the measurement by developing questions specific to only two age-group.
- *Questions are designed to capture the continuum of the disability.* The question wording and the answer categories are designed to fit the WG questions design in order to both harmonize the set of questions for children with those developed for the adult population, and to obtain a graduation of difficulty to reflect the continuum of disability and not only the presence / absence of the difficulty.
- *Questions are asked to parents or primary caregivers.* Although in principle, it would be better to assess disability through child self-report, in a survey setting it would not be reasonable in light of the young age of the potential respondent and the type of impairments that they may have. The degree of familiarity between an individual and the persons for whom they are reporting may affect the accuracy of the answer, so the parent or the primary caregiver in the household represents the best proxy respondent for questions on children.
- In an attempt to standardize the *proxy-respondents' expectations*, where appropriate, questions are prefaced with the clause "Compared with children of the same age...". This would give the respondent a point of reference in terms of child development in general and reduce the chance of the respondent making comparisons with children outside of their child's developmental stage.

Based on these principles, the working group has gone ahead by selecting appropriate and feasible ICF domains, by developing the questions - through a wide consultation process -, by validating the module mainly through cognitive tests. The last step to be taken is to establish the analytic properties of the module based on the results of field tests in progress.

Since the beginning it was recognized the efforts and gains that had been already made in the disability measurement, and that to collect documentation on childhood disability and surveys carried out was deemed important. The literature and questionnaire analysis provided a valuable basis for the initial discussions on childhood disability measurement issues, for selecting the minimum set of domains to be included in the module as well as for proposing the question wording.

Furthermore, a wide consultative process was also considered necessary for the development of the Module. Considerable effort has been placed on expanding the consultative process beyond the statisticians and survey methodologists that normally populate the Washington Group. Pediatricians have been involved at the beginning of the work and afterwards UNICEF organized a technical meeting (New York, 2012) that provided an opportunity get input from a wider audience of experts in the field of child development as pediatricians, developmental psychologists, speech therapists besides survey specialists from UNICEF. Therefore, during the ongoing development of the set of questions on child functioning and disability, changes have been made taking into account comments from experts and evidence from the validation process. The revised versions of the module have been presented to the annual WG meeting (Bermuda, 2011; Thailand, 2012; Jordan, 2013, Argentina, 2014), to which representatives also of local or of international organizations of people with disability as well as local policy makers usually participate.

As for the other WG survey measures developed, the module has undergone an extensive process of validation by cognitive tests and field tests, that aid to determine the quality of the questions and ascertain the cultural understanding by the respondents. To collect data on disability for international comparability faces important methodological challenges due to the fact that questions are administered also in different social-cultural contexts. Beliefs and attitude toward persons with disability as well as differences in language may change the perceived meaning of the questions translated and therefore influence the data reported by the respondents and be sources of systematic measurement error in survey data (Miller et al. 2011). Cognitive testing is a useful method for identifying patterns of error and patterns of interpretation across countries and socio-cultural groups as well as problems in questions due to incorrect translation or because they communicate different shades of meaning in other languages (Miller et al. 2010). Since September 2012 several versions of the module on child functioning and disability, following progress in its development, were cognitively tested in several countries: India, United States (several rounds), Oman, Belize and Montenegro. The cognitive interviews were conducted by research teams in each country with the guidance of the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS) (see Massey et al., forthcoming). Along with this activity, some preliminary field testing has also been carried out in India, Haiti and Italy, and by independent researchers in Cameroon, South Africa. The results of these research activities have been considered in the revision of the questions, even though these tests used slightly different versions of the module reflecting earlier stages of its development.

The current activities are leading to establish the analytic properties of the module based on the results of field testing in several countries that will be soon carried out. Field testing is required to gather data from the new module and compare the results with other previously developed measures of child disability, specifically the TQ and the WG extended set of questions on functioning (applied only to children aged 5 to 17). Furthermore, the objectives of the field test will include: identification of difficulties with the respondent's understanding of the questions and their ability and willingness to answer them under field conditions; testing the flow of the questions as well as the skip patterns and gauge the amount of time needed to complete the survey. In addition, the field test will provide useful information about possible specific needs for interviewer training and a rough estimate of the positive response rate in order to compute the required sample size. The field test questionnaire includes a few follow-up probe questions for certain domains of functioning, that were developed either from thematic response patterns that emerged during the cognitive testing or were designed to elicit further information on the respondent's reason for their choice of response. In addition, the follow-up probe questions help to understand the properties of certain questions and aid in establishing thresholds for inclusion into the group of children identified as "at risk".

### **3. Conclusion**

Disability is a multidimensional, complex and dynamic process, as presented in the ICF. To develop valid and concise measures of child disability for population surveys is not an easy task. Children are in a constant state of development, transitioning from infancy through childhood to adolescence and young adulthood. This implies continuous changes in their ability to perform actions and activities, especially in the early ages, therefore "the evolving characteristics of the child represent a moving target, complicating the task of assessing function and distinguishing significant limitations from variations in the normal developmental process" (Simeonsson 2006, p. 67). Furthermore, in children the main disabilities are more often related to intellectual functioning, affect and behavior and an increase of disability associated with underlying mental health problems is seen particularly in some developed countries. Those dimensions of disability are certainly more difficult to measure in the survey context. Another important issue in the measurement of child disability concerns the survey informant: the disability measurement for children takes place through the filter of a parent or some other adult caregiver and the issue related to the quality of self and proxy reports on disability is unresolved (Lee et al. 2004).

The Washington Group on Disability Statistics and UNICEF efforts have addressed these challenges and have produced a survey module tool for children 2-17 years old that when implemented will advance the measurement of child functioning and disability.

The tool is still under development as the field tests are in progress. Upon completion of the field testing, the data analysis will provide valuable information to support the understanding of specific domains of functioning and the overall module. A manual, with the technical properties of the module and methodological guidance for its implementation, will be published when the module is finalized.

The WG-UNICEF module on child functioning and disability covered, at this stage, the following domains: *vision, hearing, walking, communication, learning, remembering, emotions (anxiety/sadness), behavior, attention, coping with change, self-care, upper-body, relationships, and playing*. Not all domains are covered in both age bands identified (children aged 2-4 and 5-17), taking into account accuracy/reliability of the data that could be collected due to the level of development in children and other cultural factors. Questions are asked to parents or primary caregivers, by adopting “*difficulties in functioning*”, in accordance with the previous WG work and following other international recommendations. Difficulties in functioning are identified at the level of basic actions, “since these actions form the building blocks for more complex activities and, in an unaccommodating environment, can result in disparities in participation” (Madans et al. 2011; p. 4). This also supports data comparability since these actions are less influenced by cultural and contextual factors. Responses to questions are scaled to cover a range of levels of difficulty, for the most part, *no difficulty, some difficulty, a lot of difficulty* and *cannot do at all*. This allows for the full spectrum of functioning to be captured and allows for the selection of disability threshold best suited to the stated purpose of data collection.

Further research activities will improve the questions and will address some remaining issues such as the necessity to include other domains or the feasibility of administering the module directly to children (from a certain age) by changing the wording in an appropriate way.

As already stressed, the “WG-UNICEF Module on child functioning and disability” is intended to identify the sub-population of children and youth “at greater risk” of experiencing limited social participation than children of the same age. The implementation of this module will aid in the production of comparable data cross-nationally that, in combination with other data collected on specific topics can be used to determine the degree to which children and youth with disabilities are able to participate in society compared with those without disabilities. These data will support a country’s ability to monitor and assess compliance with the UN Conventions and, over time, its progress towards the full implementation of the rights of children with disability.

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