

Measuring child functioning: the Unicef/ Washington Group Module*

Mitchell Loeb,⁽¹⁾ Claudia Cappa,⁽²⁾ Roberta Crialesi,⁽³⁾ Elena de Palma.⁽³⁾

The Convention on the Rights of the Child, adopted in 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).¹ The Convention on the Rights of Persons with Disabilities further strengthened the rights of children with disabilities with a dedicated article on children (art. 7).² This article 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 challenges 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 develop-

ment, implementation and evaluation of policies and programs that would improve the lives of children with disabilities.

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.

The WG chose to use the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) as the conceptual framework for the development of question modules.³ 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 and colleagues.⁴ In short, the WG approach to disability measurement identifies six basic, universal activity or functioning domains (seeing, hearing, walking, remembering and concentrating, communicating and self-care) where respondents may experience difficulty functioning in their environments.

*This special note is based on the working documents of the Unicef/WG Child Functioning workgroup and work that has been previously published in International Measurement of Disability: Purpose, Method and Application – The work of the Washington Group on Disability Statistics. B. Altman (Ed).

(1) CDC and National Center for Health Statistics. Hyattsville, MD, USA.

(2) Data and Analytics Section, Unicef. NY, USA.

(3) Italian National Institute of Statistics. Rome, Italy.

Received on: March 29, 2017 • **Accepted on:** June 30, 2017

Corresponding author: Claudia Cappa. Data and Analytics Section Unicef. 2 UN Plaza 10017 New York, NY, USA

E-mail: ccappa@unicef.org

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 (defined based on per capita gross national income).^{*} 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 WG for the development of a joint module.

Milestones in the development of the Unicef/WG Module on Child Functioning

Selection of appropriate and feasible domains of functioning and question design

Questions were developed according to a range of domains identified through the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY),⁵ and survey questionnaire already in use in several countries. Based on this assessment, an initial set of domains was selected: seeing, hearing, mobility, communication/ comprehension, learning, relationships, and playing. These were the most common domains found in existing survey questionnaire, but because child disability comprises a wide range of domains, reflecting child development, additional domains of functioning were developed and included: emotions, behaviour, focusing attention/ concentrating and coping with change.

It was important that question design avoided a medical approach (that focuses on impairments or conditions), and rather operationalized the biopsychosocial model. Questions focused on a particular aspect of the ICF (difficulties doing basic, universal activities) that would identify children at risk of restricted participation in a non-accommodating environment. The workgroup felt it would be beneficial to use, when appropriate, the questions already tested and adopted by the WG; and to conform to established WG question/response

design in order to both harmonize the child functioning questions with existing WG products and to capture the continuum of difficulty.

Development of age cohorts and proxy respondents

While, recognizing the importance of early detection of children with functional difficulties, it is extremely challenging to capture children under 2 years of age through surveys designed for research purposes. 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.

Furthermore, questions were developed in a way that would be appropriate for two specific age cohorts: pre-schoolers age 2-4 years and school-aged children 5-17 years.

As mentioned earlier, it was determined that questions would be directed to a proxy respondent, the child's mother or primary caregiver. In order to standardize the expectations of the proxy-respondents to focus their attention on the functioning of their own child in relation to the child's age, the questions, where appropriate, are prefaced with the clause: "Compared with children of the same age...".

Validating the module

Question design is an iterative process of drafting, test, revision, retest etc. Question evaluation through cognitive testing was used to evaluate the cross-cultural equivalence of the Module, verifying that the questions were understood according to their intent, and applicable to the widest range of respondent's life contexts. Following previously established WG validation procedures, the Child Functioning Module underwent initial cognitive testing in 2012 and 2013 in India, Belize, Oman, Montenegro, and the USA.⁶

The results of cognitive testing were presented in Amman, Jordan 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, Argentina in October 2014.

^{*} www.un.org/en/development/desa/policy/wesp/wesp.../2012/country_class.pdf

A separate cognitive test was conducted in the USA in 2015, specifically to evaluate the differences in how the same questions are interpreted/answered by the teens and by their parent-proxies. The results showed that while teens often have greater insight into the specifics of their difficulties, there were high levels of agreement indicating that parents provide accurate information on their teens' difficulties and in some domains the parent's understanding of the meaning of the question was more in line with the intent.⁷

Field testing on the module began in Samoa in July 2014 by the Samoa Bureau of Statistics.* The Child Functioning module was included in the Samoa Demographic and Health Survey 2014. Preliminary findings, presented at the 15th WG meeting in Copenhagen, Denmark 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.

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.

Establishment of analytic properties of the module

Disability may be a complex 'process' involving body functions and structure, activity limitations and participation restrictions, personal characteristics – and not least aspects of environmental barriers and facilitators. The determination of disability status (based on difficulties doing basic activities), on the other hand, need not be complex. The graded responses to the questions in the Unicef/WG Child Functioning Module allow for the generation of several thresholds or cut-offs for determining disability in a population. It is possible to determine the proportion of those who have mild difficulties (at least *some difficulty* on one or more domain of functioning), or moderate levels of difficulty (those who respond at least *a lot of difficulty*) or those with severe difficulties (those who respond *cannot do at all*). Since disability is not a simple, single yes/no dichotomy, guidance is provided on producing several disability indicators based on the above cut-offs. In addition it

is the recommendation of the Unicef/WG collaboration that the cut-off at the level of *a lot of difficulty* be operationalized for reporting data internationally, and for the disaggregation of outcome indicators (like school attendance) by disability status.

Based on the analysis of field test data, computer syntax was generated (in SPSS) that provides the information necessary to compute these disability indicators.

Conclusion

The work of the Unicef/WG collaboration provides a standard way to identify, at the population level (censuses and surveys), the prevalence of functional difficulties among children aged 2 to 17 years, and to use this information to monitor participation (for example, access to education) in accordance to the Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. These data may help countries and governments plan and develop better practices to improve the living conditions and well-being of children with disabilities around the world.*

Official translations are currently available in Spanish and Vietnamese. Translations into the other official UN languages (Arabic, Chinese, French, and Russian) are pending.

<https://doi.org/10.21149/8962>

Referencias

1. UNICEF. Convention on the Rights of the Child. Geneva: UNICEF, 1989. Available at: <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>
2. United Nations. Convention on the Rights of Persons with Disabilities. Geneva: UN, 2006.
3. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization, 2001.
4. Madans JH, Altman BM, Rasch EK, Mbogoni M, Synneborn M, Banda J, et al. Washington Group Position Paper: Proposed Purpose of an Internationally Comparable General Disability Measure. 2004. Available at: http://www.cdc.gov/nchs/data/washington_group/WG_purpose_paper.pdf
5. World Health Organization. The International Classification of Functioning, Disability and Health for Children and Youth: ICF-CY. Geneva: World Health Organization, 2007.
6. Massey M, Chepp V, Zablotsky B, Creamer C. Analysis of Cognitive Interview Testing of Child Disability Questions in Five Countries. NCHS, 2014. Available at: <http://wwwn.cdc.gov/qbank/NewReports.aspx>
7. Massey M, Scanlon P, Lessem S, Cortes L, Villarreal M, Salvaggio M. Analysis of Cognitive Testing of Child Disability Questions: Parent-Proxy vs. Teen Self-Report. NCHS, 2014. Available at: <http://wwwn.cdc.gov/qbank/NewReports.aspx>

* 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 finalized UNICEF/WG Module on Child Functioning is available on the WG website: <http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/> and on the UNICEF website: <https://data.unicef.org/topic/child-disability/child-functioning-module/>