



# Measuring child disability cross-nationally: development and validation of the “UNICEF-WG Module on Child Functioning”

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# Background

- The quality and quantity of data available on child disability vary enormously across the World, and several factors undermine their cross-national comparability
- To measure child disability, a standard set of questions must be developed in alignment with the ICF-CY classification of the specific aspects of child development and disability (WHO, 2007)
- The “**UNICEF-WG Module on Child Functioning**”, developed by the UN Washington Group on Disability Statistics (WG) and UNICEF, aims to produce reliable and internationally comparable data collected through population surveys

# The Module

- **Objective:** to identify the sub-population of children and youth (aged 2-17) with functional limitations who are “at greater risk” of experiencing limited social participation compared to children of the same age group
- **Aim:** to provide cross-nationally comparable data
- **Domains:** Seeing, Hearing, Walking, Communication, Learning, Playing, Relationships, Dexterity, Behavior, Attention, Self-care, Emotions, Coping with change. *Not all domains are covered for all age, depending on the accuracy/reliability of collectible data based on child's development stage and cultural factors*
- **Questions:** aimed at parents/primary caregivers
- **Answer categories:** designed to reflect a continuum in functioning difficulties enabling the determination of appropriate cut-offs based on disability data collection requirements
- **Usability:** in national population surveys or as supplement on specific topics of interest

## Development of the Module: main steps

*The **WG Child Functioning Working Group** (NSO reps. from both developed and developing countries) followed these main steps in developing the Module:*

- Drafted/revised the questions
- Conducted Multiple rounds of CT
- Finalized the questions
- Conducted Field Tests
- Finalized the Module

*Preparation*

*Development & Validation*

*Fostering*

- Established guiding principles
- Reviewed literature
- Assessed existing questions/ tools
- Consulted child development specialists/ other survey methodologists

- Developed interviewer guidelines/user manual
- Professional translation of the module
- Planned capacity building activities

- **Determination of the appropriate target population**

*Despite the importance of early detection, child development itself makes it difficult to distinguish between significant functional limitations and variations in normal developmental process, especially in children under 2 years.*

*As targeting children aged 0-2 is likely to produce inconsistent and ambiguous results, these were not included in the target population*

- **Selection of feasible domains & production of a concise module**

*While child disability comprises a wide range of domains, some of which may require more than one question for an accurate assessment, there was the need to identify an essential set of domains.*

*A review of the literature and a mapping of the questions in use vs. the ICF-CY checklists led to a parsimonious set of domains that reliably describe the main functional difficulties faced by children*

- **Self vs. Proxy respondent**

*Generally, disability measurement for children takes place through proxy. Even though this may introduce some bias, parents can actually facilitate the assessment of children over a wide age range.*

*Considering the standard survey methodology, ethical considerations, the children's ability to answer questions about their own difficulties in relation to their peers, and their possible health condition, it was decided to use parents/primary caregivers as proxy*

- **Steering proxy-respondents**

*Parents relies on their observation and expectations for the child.*

*Some questions were prefaced with: "Compared with children of the same age..." in order to provide a point of reference in terms of child development in general and reduce the chance of the respondent making comparisons with children of other developmental stages*

- **International comparability**

*Children learn to perform actions at different speeds, influenced also by specific socio-cultural factors. So, while reviewing survey questions/tools...*

*... actions applicable to all children regardless of nationality/culture were identified, with the help of child development experts*

- **Reduction of complexity**

*To obtain precise information on functional limitations, questions must address actions that are specific to narrow age ranges, but...*

*... to make the Module easier to administer, it was sought to balance accuracy and usability targeting actions applicable to wider age ranges: 2-4 and 5-17 years*

- **Fostering worldwide adoption**

*In most countries data are collected through PAPI, and resources for survey administration and enumerators' training are often scarce, therefore...*

*... it was essential, to ensure the international comparability of the new survey measures, to produce a detailed user manual and to plan capacity building activities*

## Validation of the Module

*Since 2012, under the guidance of the Questionnaire Design Research Laboratory of the US National Center for Health Statistics (QDRL), several rounds of **cognitive tests** (USA, India, Belize, Montenegro, Oman, Jamaica) and **field tests** (Samoa, El Salvador, Serbia,) have taken place.*

### Training of CT interviewers

- **QDRL provided intensive training courses** in each country for cognitive interviewers to ensure comparability of the data collected
- **Each country recruited interviewers** from statistical offices and/or organizations working in the field of disability
- **Contents of interviewers' training courses:** CT goals, Methodology, Testing protocol, Procedures, Notes taking, Analysis of cognitive interview data using the Q-Notes software, and Reporting
- **Mock interviews were extensively conducted** among the course attendants, and also with samples of real respondents, in order to ensure proficiency in administering the cognitive test



## Validation of the Module

**Three rounds of CTs** were carried out in the USA, Oman, India, Belize and Montenegro for a total of 258 interviews. The main goals were:

1. *Assess respondents' interpretation of the questions*
2. *Identify potential responses problems that could impact data quality.*

## Cognitive Tests

- **CTs were 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
- **Each county recruited a purposive sample of parents/primary caregivers of children aged 2-17** who may or may not have difficulties in the domains selected - covering a variety of ethnicities, primary languages and socio-economic conditions
- **Respondents were remunerated for their time**
- **English questions were translated** into local languages. Native speakers conducted one-hour (on average) face-to-face interviews (typically videotaped and audio recorded)

## Data collection

- **Retrospective, intensive verbal probing**
- Probes included such questions as:
  - ✓ *Why did you answer the way that you did?*
  - ✓ *How did you arrive at your response?*
  - ✓ *Can you tell me more about that?*
  - ✓ *Can you clarify what you mean?*

## Data analysis

- Data collected in each country were analyzed locally and summarized in a country report for the QDRL's examination, using Q-notes
- **Analysis process involved synthesis and reduction of the qualitative data through 5 incremental steps:**
  - ✓ Conducting interviews
  - ✓ Producing summaries of questions' interpretation and answers
  - ✓ Comparing across respondents to identify common themes
  - ✓ Comparing across sub-groups of respondents to identify differences depending on personal experiences/cultural backgrounds
  - ✓ Reaching conclusions on question performance

## Validation of the Module

*A further 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*

### Parent-proxy CT

- Purposive sample of teens aged 12-17 with/without difficulties and their parent-proxies (80 interviewees in total)
- Retrospective, intensive verbal probing
- Results proved that the members of the dyads used similar patterns of interpretation with a higher level of agreement in the observable domains, and more divergent patterns in the less observable domains
- While teens often have greater insight into the specifics of their difficulties, parents can provide fairly accurate information on the impact of their teens' difficulties on their functioning
- **Since the focus on functioning aligns with the original intent of the questions, the use of parent-proxies to assess teen difficulties is appropriate**

- **Wording simplification**
- **Elimination of examples when inappropriate in some cultural contexts**
- **Elimination of the preface “compared with children of the same age...” where this was deemed unnecessary and when question refers to less observable domains**
- **Adoption of the best wording when more options were tested**
- **Reduction of the number of questions to the minimum required to capture the population for each domain**
- **Inclusion of additional questions for some domains**
- **Modification of answer categories**

# Final remarks



- An effective international survey tool needs to strike for a **balance between domain selection** (number and relevance), **simplicity of the tool** (number of questions and skip patterns) and **accuracy of the assessment**. Since the questions aim to capture the intended concepts in an international context, a cross-cultural investigation of the questions' performance is an absolute must
- The **UNICEF-WG Module on Child Functioning** module is a rigorously tested method of identification of children with disabilities in surveys. Developed with input from a variety of experts and stakeholders to be in line with the concept of disability underlying the ICF and the CRPD, it has undergone a series of cognitive and field tests that have proven the questions to be straightforward to administer and well understood by respondents

# References

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**For further information:**

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