

The WG/UNICEF module on child functioning and disability: from Constructs to Questions in Mumbai

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WG/UNICEF Module on Child Functioning and Disability

Background information

To overcome the lack of internationally comparable data on child disability, the Washington Group on Disability Statistics (WG) is developing a **survey module** in collaboration with UNICEF.

The primary purpose is: **to identify the sub-population of children and youth (aged 2-17 years) who are “at greater risk”** than the children of the same age of experiencing limited social participation.

The module is intended to be used as a component of national population surveys or as a supplement to specialized surveys (health, education etc.) **to provide cross-nationally comparable data.**

WG/UNICEF Module on Child Functioning and Disability

Background information

In developing the module the group has:

- ✓ used the ICF-CY as conceptual framework
- ✓ reviewed studies carried out on the development of measures of child disability as well as national and international surveys on child disability
- ✓ consulted experts (paediatricians, developmental psychologists, speech therapists ..) and held two consultative meetings in 2012: Rome/Italy & NY/USA
- ✓ presented and discussed during two WG annual meetings

The module will be validated through cognitive and field testing, following established WG procedures.

CT has been completed in India and USA; is being finalized in Belize; is scheduled for Oman (April 2013); planned for Montenegro later this year.

WG/UNICEF Module on Child Functioning and Disability

SELECTED DOMAINS

Vision Hearing Walking Self-care Communication
Learning Emotion Behaviour Attention Coping with change
Relationship Playing

Questions:

- focus on functional difficulties,
- *with reference to the child's age cohort;*
- are asked to parents or primary caregivers;
- utilize response options to reflect the disability continuum.

Response categories are:

- 1) No difficulty 2) Some difficulty 3) A lot of difficulty 4) Cannot do at all

To produce comparable data cross-nationally on child functioning and disability

Proposed questions

Because the questions should identify children with a similar type and level of limitations in activity functioning, regardless of where in the world they live, a set of basic actions or universal activities were selected. Furthermore, when an example is needed the country can choose the most culturally appropriate.

Cognitive tests

The cognitive test is a useful method for identifying patterns of error and patterns of interpretation across countries and socio-cultural groups as well as problems in question design: questions that have been incorrectly translated or that convey different shades of meaning in other languages (Miller et al. 2011).

Translation and Cognitive test in India

Purpose of translation

is to produce instruments that maintain equivalence of measurement across languages/dialects and to achieve a functionally equivalent and culturally appropriate version of the original instrument.

The module has been translated in Hindi, as it is the national language as well as being easily understood by a majority of the population in Mumbai.

As a first step, the questionnaire was translated in Hindi initially by using an online translator.

A small group involved in the cognitive test revised this version, correcting errors and re-wording from “academic” Hindi to a vernacular version that would be more easily understood.

This version was then discussed in small, in-class consultations that resulted in a final translated version of the module.

Translation and Cognitive test in India

The module was cognitively tested in Mumbai last September.

72 cognitive interviews were conducted.

The cognitive testing was carried out in three rounds.

After each round the research team conferred to see if there were any major problems in interpretation.

When clear problems existed with the questions they were modified to try to rectify these problems prior to next round.

For “**walking**” domain changes needed to be made.

Walking: original questions

The purpose of these questions was to identify children with varying degrees of difficulty walking.

Children aged 2-4 years

3a) Compared with children of the same age, does [name] have difficulty walking?

Children aged 5-17 years

3b) Compared with children of the same age, does [name] have difficulty walking 500 meters on level ground?

(That would be about.... *[Insert country specific example]*)

Only for answers **some/a lot difficulty or cannot do at all** to 3b:

3c) Compared with children of the same age, does [name] have difficulty walking 100 meters on level ground?

(That would be about.... *[Insert country specific example]*)

Walking:

For children aged 2-4:

- children whose difficulties created barriers to playing, and exploring and interacting with their environment and their community in a way that excludes them or have a negative effect on their development.

For children aged 5-17:

- the *short distance* question is meant to identify children whose level of difficulty in walking would affect their ability to care for themselves in their immediate environment.
- the *long distance* question is meant to identify children who experience difficulties undertaking normal childhood activities outside the home – like attending school, participating in cultural or recreational events, etc.

Walking

1° round of testing:

Respondents:

- were able to compare the child with other children, and also compared the child's walking pattern at different points in time.
- could easily answer the question for the age range of 2-4 years
- had problems understanding the questions for walking in the age group of 5-17 years as the **distances measured (500 meters and 100 meters) were an abstract number for them**, which were had difficulty differentiating.

Questions for 2° round:

Children aged 5-17 years

3b) Compared with children of the same age, does [name] have difficulty walking **Half a kilometre** (1/2 km) on level ground?

Only for answers *some/a lot difficulty or cannot do at all* to 3b:

3c) Compared with children of the same age, does [name] have difficulty walking **200 steps** on level ground?

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Walking

2° round of testing:

Respondents were able to understand and visualize the distance, but the examples they provided were subjective and not specific to a short or longer distance.

One could not be sure of the respondent's correct understanding of the long and short distance.

Changes in questions for the 3° round:

keeping in mind the original rationale for the questions:

- the order of the questions was changed: short distance followed by longer distance
- the skip pattern was eliminated
- a concrete example introduced in the question itself
- the reference to the evenness of the ground was eliminated

Walking

Questions for Round 3:

Children aged 2-4 years

3a) Compared with children of the same age, does [name] have difficulty walking?

Children aged 5-17 years

3b) Compared with children of the same age, does [name] have difficulty walking **a short distance** for example across a large room?

3c) Compared with children of the same age, does [name] have difficulty walking **a longer distance** for example to a store?

Conclusions

- The example provided is specific to the experience in Mumbai only.
- The sample module has been/will be tested in USA, Belize, Oman and Montenegro.
- It is not certain yet that other countries will experience similar issues with these questions-or this particular domain.
- This example has been provided as an illustration of a single country's experience with a specific question that was developed for global testing – issues of translating concepts into Hindi – and a local resolution to problems that arose in the process.
- The final version of the module will be the result of the cross-national analysis of results of cognitive testing from all the participating countries.