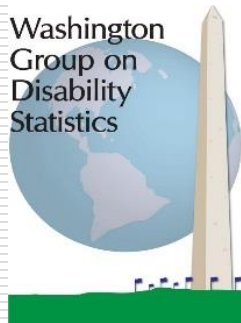# Collecting Disability Data

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Challenge

How to measure the broad experience of disability through a limited number of questions in a consistent and comparable way?

What we have learned that works and what doesn't work

Adoption of the WG-6

The WG routinely monitors the collection of disability data internationally, and annually requests detailed information from representatives from NSOs:

- survey periodicity,
- sample size and frame,
- mode of data collection,
- language(s) used,
- the actual questions/response options used
- and prevalence data.

Overview of disability data

In a recent review, 43 countries submitted tabular data:

- 8 Middle East
- 10 North/South America
- 7 Europe
- 12 Asia/Pacific
- 6 Africa

(Countries were asked to provide their most recent data – and years ranged from 2002 to 2013; however, the majority of data submitted fell within the 2010 census cycle.)

We have found that while countries have reported disparate disability prevalence rates; those that use the WG *as intended* have reported disability prevalence rates that are comparable:

- Israel census/2008   6.4
- Aruba census/2010   6.9
- Turkey census/2011   6.9
- Zambia survey/2006   8.5
- Maldives survey/2009   9.6
- USA survey/2011,12,13   8.5/7.9/9.5

(samples differ in age ranges included)

However…

Even the best questions…

Because of a Health problem:
1) Do you have difficulty seeing even if wearing glasses?
2) Do you have difficulty hearing even if using a hearing aid?
3) Do you have difficulty walking or climbing stairs?
4) Do you have difficulty remembering or concentrating?
5) Do you have difficulty with (self-care such as) washing all over or dressing?
6) Using your usual language, do you have difficulty communicating (for example understanding or being understood by others)?

Response categories:
No - no difficulty; Yes - some difficulty;
Yes - a lot of difficulty; Cannot do at all

…will fail if a screener is added

Is the person *suffering* from any difficulty/*disability* in the carrying our everyday activities? (prevalence 3.2%)

…or if the wording of the question is negative

Terms such as *disabilities* and *handicaps* are viewed as negative and tend to underreport disabilities.

Suffering may be associated with disease or illness but not necessarily with the life experiences of a person with disability. This language may also negatively influence the self-reporting of functional difficulties.

Response categories

Avoid Yes/No response dichotomies.

They tend to force the respondent into a category they may not want to self-identify with – Given the option, they may choose 'No'

Scaled response are preferable:

- No/Yes, a little/Yes, a lot/Cannot do at all

It has been shown that scaled responses improve the respondents' ability to report.

Issues to consider:

Adapting existing tools

- Translation
- Cultural appropriateness

Administration of questionnaire and interviewer training

Adapting Existing Tools: Translation

Translation is required for existing tools to ensure:

- Culturally appropriateness
- The constructs of the question are being adequately captured

Proper translation into the primary language(s) of the country

- Reduces differences in question interpretation
- Increases reliability and validity of data collected

Adapting Existing Tools: Translation

Methods of translation:

- Literal/word for word (Forward/back translation)

- Non-literal – concept based (Team translation)

- Computer based (NO!!)

Adapting Existing Tools: Translation

Forward/Back translation:

- Translation to the new language

- Independent translation back to original language by one individual

- Compare two versions

Team translation (by consensus):

- Translation to new language by two or more translators

- Translators and an independent reviewer meet to review and comment on issues or changes to recommend

- An adjudicator ultimately will decide on changes /recommendations to adopt

- Reviewed translated version is pretested

Adapting Existing Tools: Translation

Translators require:

- very good knowledge of the source language
- an excellent command of the target language
- familiarity with the subject matter and the intent of the questions
- sense of when to translate literally and when to translate conceptually

A competent translator is not only bilingual but bicultural

Adapting Existing Tools: Culture Appropriateness

Careful review of existing content of questions

- Assure cultural relevance of concepts, skills or references
- Avoid gender and other biases

Adapting Existing Tools: Translation

Questions AND answer categories need to be carefully translated

Example: Seeing

Do you have difficulty seeing (even if wearing glasses)?

- The purpose of this item is to identify persons who have any kind of difficulties or problems seeing even when wearing glasses (if they wear glasses).

- Seeing refers to an individual using his/her eyes and visual capacity in order to perceive or observe what is happening around them.

- Included are problems seeing things close up or far away.

- Included are problems seeing out of one eye or only seeing directly in front but not to the sides.

- Any difficulty seeing that is considered a problem is included.

Example: Response options

- The 4 response options describe a continuum of difficulty.

- The endpoints *no difficulty* and *cannot do at all* anchor the continuum and are probably easier to translate.

- The spread of the continuum is further defined through categories *some difficulty* and *a lot of difficulty*.

- It will be important for the translators to select descriptors into approximately 3 equal pieces so as to capture the maximum amount of variation in functioning.

Development of a comparable testing methodology

Development of a comparable testing methodology

With an emphasis on evidence and transparency – the WG embarked upon the development of a question evaluation methodology that relied on extensive testing of questions in multiple countries.

Cognitive testing allows us to determine how respondents understand and interpret the question.

- Do individual respondents understand the survey question differently?

- Do they interpret the question as intended?

- Does the question mean the same in all the languages, cultures and socio-economic groups that it is asked?

Comparable testing methodology:

- Developed a procedure for question evaluation that includes guidelines for translation and cognitive testing in order to ensure cross-cultural and cross-national comparability

- Q-Notes software developed for data entry and analysis of qualitative cognitive interviews

- Q-Bank launched as an online repository for reports of question evaluation studies – to ensure transparency

Testing of the WG SS

Cognitive testing of the short set was carried out in 2006 in 15 countries:

- Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda, Vietnam

This was followed by field testing in five countries:

- Argentina, Brazil, Gambia, Paraguay, Vietnam

WG SS adopted in 2006

Testing of the WG Extended Set

2009:

- Cognitive and field testing carried out in six UNESCAP countries: Cambodia, Kazakhstan, Maldives, Mongolia, Philippines and Sri Lanka

- Cognitive testing also carried out in Canada, USA and South Africa

2010:

- European/US cognitive testing in US (English/Spanish), Spain, Germany, Switzerland, Italy, France, Portugal

- Cognitive testing in Oman.

- UNESCAP Round II cognitive testing in Sri Lanka, Cambodia, Philippines, Maldives, Mongolia, Kazakhstan

WG extended set adopted in 2010

Testing of the WG/UNICEF Module on Child Functioning:

Cognitive testing:

- September 2012, India
- January 2013, Belize
- April 2013, Oman
- July 2013, Montenegro
- 2012/13/14, USA
- 2016 India & Jamaica

Independent field testing in: Haiti, Italy, India, Cameroon, Samoa, Myanmar, El Salvador, Zambia

Final round of field testing in Serbia – 2016

WG/UNICEF child functioning module launched 2016

Cognitive Testing of Translations:

- The cognitive testing of the WG questions was done in multiple languages

- Cognitive testing of new translations will assure that the translation captures the intent of the question and the answer categories

- Reference: Cognitive Interviewing Methodology, K Miller, S Willson, V Chepp & JL Padilla (eds), Wiley, 2014.

Interviewer Training/Instructions:

It will be essential that interviewers are carefully selected and that they undergo thorough training not only in basic question/response techniques, but also in disability as subject matter.

A few basics:

- Ask the questions as they are written. Don't improvise – or translate on the fly.

- Make sure the respondent answers each question. Don't assume a response by observation.

- The questions aren't sensitive – they concern universal basic activities that all people, regardless of nationality or culture, should understand.

- If the interviewer is uncomfortable, the respondent will be so too – so they need to be familiar with the material – and relax.

- Prepare – meet with disability groups, practice interviews if possible before going into the field.

Answers to some frequently asked questions:

Introductory statement:

'*The next questions ask about difficulties you may have doing certain activities because of a health problem*'

- Included for the purpose of transitioning from topic to topic in a census context and format.
  - small number of questions on different topics with topics changing quickly.
- Purpose: to inform the respondent that the next set of questions had a health context.

Temporary or long-term difficulties:

- The WG SS does not address duration -- No mention of 'usual functioning' vs 'temporary difficulties'.

- Testing showed that answers to the short set of questions, more often than not, refer to usual difficulties.

  - For example, if someone has a broken leg – and temporarily has difficulty walking – that person tends to answer no difficulty because usually they do not have any difficulty and as soon as the cast is removed, they will return to their normal state.

Temporary or long-term difficulties:

- Targeting only long-term difficulties would require a long, complex introductory section.

    - Respondents seldom listen to all of the instructions when survey modules are preceded with such long and wordy opening statements.

        The next questions ask about difficulties you may have doing certain activities only because of your HEALTH.

        Please think about the last 30 days taking both good and bad days into account. Only consider difficulties that have lasted or are expected to last for 6 months or more.

Temporary or long-term difficulties:

- A respondent has to think of, and remember, all those instructions when answering the questions that follow.

- Cognitive testing has shown that they do not always take these considerations into account when they respond.

- Respondents may focus on the instructions at the beginning of the statement or at the end, but they do not recall or consider all, or at times, any of the instructions.

Administration of the questions:

- Response options should be read aloud as part of each of the six questions as follows:

Do you have difficulty walking or climbing steps? Would you say:

- No, no difficulty
- Yes, some difficulty
- Yes, a lot of difficulty
- Cannot do it at all.

- If respondents become familiar with the answer categories after the first few questions, the recommendation to repeat the categories can be relaxed.

Placement in a census or survey:

- The module of six questions is best situated

  - at the beginning of a survey questionnaire (together with the demographic information collected on household family members) or

  - towards the beginning of a section that deals with health information.

- It is recommended that the module not be added on at the end of the questionnaire.

The use of proxy respondents:

- Ideal situation -- self-report with the exception of those who are not capable of responding themselves.

- In surveys, particularly in censuses, where it is common to have a primary respondent report for all other household members, proxy response is acceptable.

- No one should be excluded because they cannot respond on their own due to difficulties functioning.

Age suitability:

- WG SS designed for a census context (general population 5 years of age and above)

- Disability in children, due to the circumstances of child development and transition from infancy through adolescence, is not adequately covered by these questions.

- In the absence of other measures or other data collection exercises, these questions will provide an indication of child functioning in the domains covered for the population 5 – 17 years of age but will miss functional domains important for children.

On the use of assistive devices:

- Intent of the WG SS: record, with the exception of seeing and hearing, difficulties people have with <u>unaccommodated</u> functioning (without the use of assistive devices/assistance).

- Rationale: intent is to identify difficulties in functioning that may put a person at risk of limited or restricted participation (in employment or education, family or civic life etc.).

- That risk of restricted participation – in the absence of accommodations – is 'disability' as defined by the UN CRPD.

Questions?