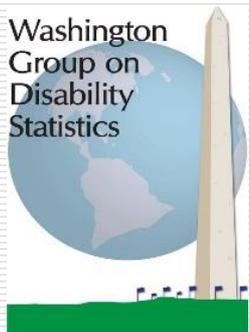


Collecting Disability Data



PRESENTED AT: Washington Group on Disability Statistics
Regional Implementation Workshop
Trinidad & Tobago
2017

Collecting Disability Data

National Center for Health Statistics, USA
and
Washington Group on Disability Statistics

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Port of Spain, Trinidad & Tobago
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The Challenge

How to measure the broad experience of disability through:

- a limited number of questions,
- in a consistent manner,
- in a cross-culturally comparable way?

Meeting the Challenge

Developing the reliable tool requires:

- thorough and careful testing methods,
- testing across as many countries and cultures as possible.

Obtaining the quality data requires:

- careful translation,
- comprehensive interviewer training,
- accurate administration.

Testing the WG Tools

Cognitive Testing of the WG SS

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.

Goals for Question Evaluation:

- How do the respondents understand the survey question?
- Do respondents understand the survey question differently?
- Does the question mean the same in all the languages that it is asked?
- Does the question mean the same in all culture and socio-economic groups that it is asked?
- In processing a question, do all respondents recall information and form an answer the same way?

Goals for Question Evaluation:

- To what extent are the data elicited from the question a true representation of the phenomena being studied?
- In what ways is our picture distorted because the questions do not accurately capture the intended construct?
- What important discovery are we not making because we are unaware that our picture is distorted?

Why Question Evaluation?

1. To fix problems
2. Ensure comparability
3. Documentation
 - Development and evaluation process
 - “What the question captures”
 - How resulting data should be used
 - “Road map” for including question on other surveys, in other languages, in other socio-cultural contexts

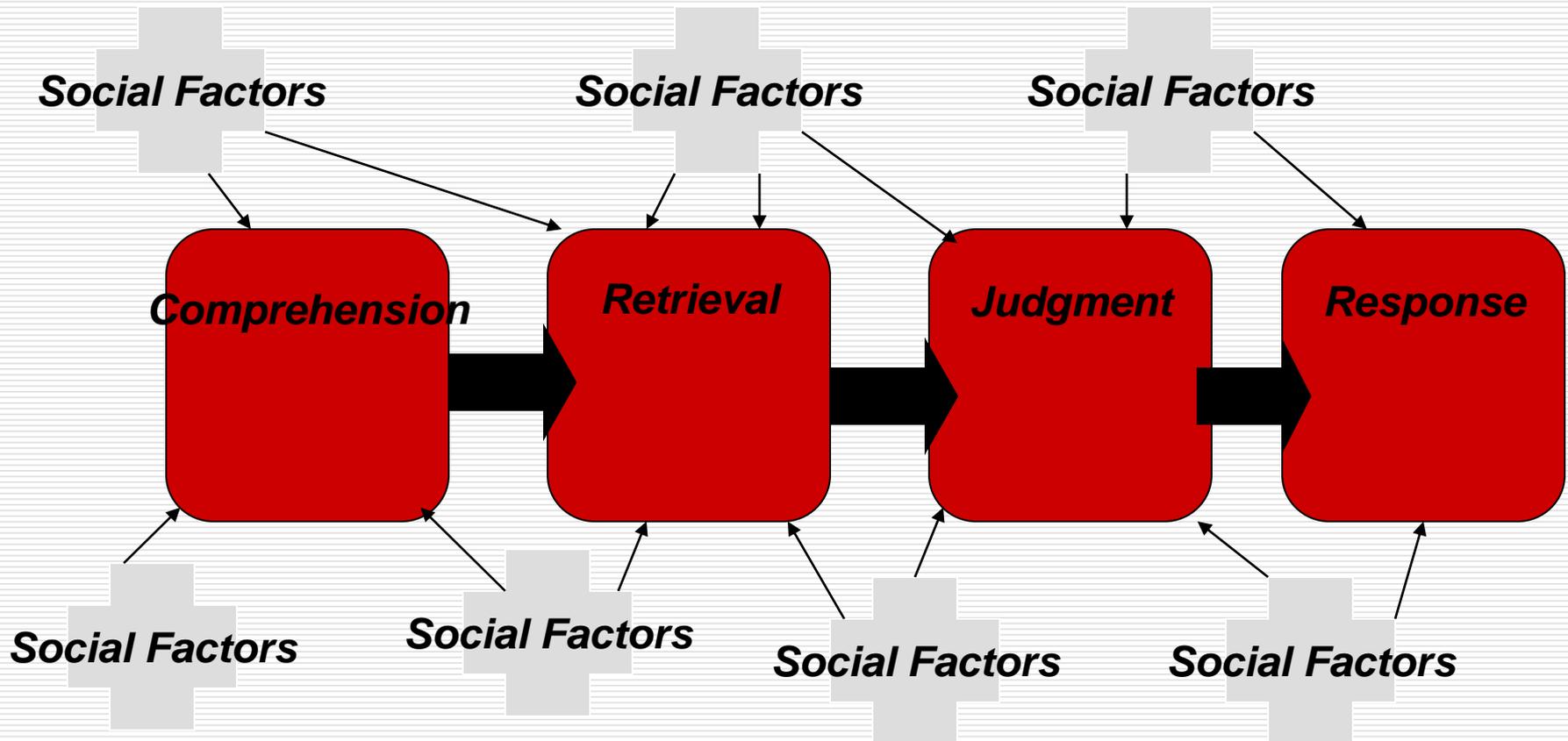
Question Evaluation Principles

1. The best question design is based on question evaluation, not expert opinion
2. Question evaluation is science-based
 - Empirical Evidence
 - Transparent & Systematic analysis (Q-Notes)
3. Evaluation studies must be well documented, replicable, and made accessible (Q-Bank)

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

Question Response Process



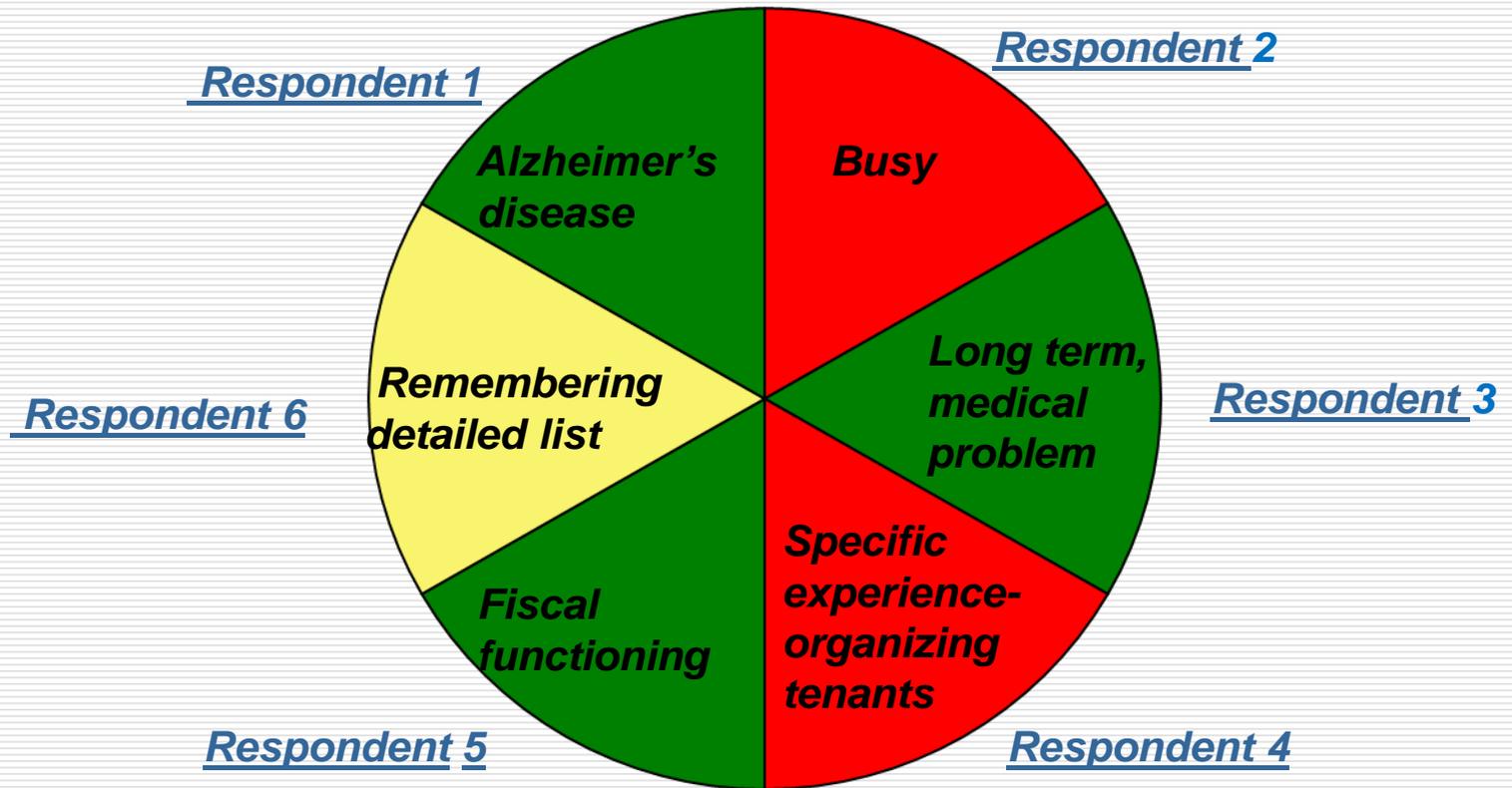
The Cognitive Test Approach

- Cognitive interviews are semi-structured.
- The approach adopted is a mix of think-aloud and verbal probing based on a common testing protocol.
- Probes are open-ended, not pre-scripted, and spontaneous - based on the information provided by the respondent.

Some suggested probes:

- How did you come up with this answer?
- Why did you answered in that way?
- What were you thinking?
- Can you tell me more about that?
- What do you mean by that?

Overall, during the past 4 weeks, how much difficulty did you have with thinking clearly and solving daily problems?



Cognitive Testing of the WG tools

2006 – Cognitive testing of the WG-SS:

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

2009/10 – Several rounds of Cognitive testing of the WG-ES:

- six UNESCAP countries: Cambodia, Kazakhstan, Maldives, Mongolia, Philippines and Sri Lanka;
- also in Canada, USA, South Africa, Spain, Germany, Switzerland, Italy, France, Portugal, and Oman.

2012-16 – Cognitive testing of the WG/UNICEF CFM:

- India, Belize, Oman, Montenegro, USA, India and Jamaica.

Cognitive Testing of Translations

- 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.

What works and what does not...

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 *disability* in the carrying out everyday activities?

Resulting in very low prevalence: 3.2%

...or if Negative Wording is added

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.

...or if the Responses are changed

Avoid response dichotomies:

Yes / No

They tend to force the respondent into a category they may not want to self-identify with.

Given the option, respondents may choose **No**.

Scaled responses are preferable:

No / Yes, some difficulty / Yes, a lot of difficulty / Cannot do

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

Administration Issues to Consider

When adopting existing tools into data collections, a number of considerations are important:

- Translation
- Cultural appropriateness
- Comparable testing
- Administration of questionnaire
- Interviewer training

Adopting Existing Tools: Translation

Translation is required and ensures:

- Cultural appropriateness
- Question constructs are adequately captured

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

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

Adopting Existing Tools: Translation

Methods of translation:

- Literal: word-for-word
(forward/back translation)
- Non-literal: concept based
(team translation)
- Computer-based: **No!**

Adopting 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 and make recommendations for adoption
- The reviewed translated version is pretested

Adopting 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

A competent translator is not only bilingual but bicultural.

Adopting Existing Tools: Cultural Appropriateness

Careful review of existing content of questions.

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

Using 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.

Interviewer Training/Instructions

It is essential that interviewers are:

- carefully selected, and
- undergo thorough training (not only in basic question/response techniques, but also in disability as subject matter).

Answers to Some Frequently Asked Questions

The 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.
- 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 – There is 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 walking. The reference for respondents tends to be 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.
- Example of a challenging introduction:
 - 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 unaccommodated 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.

In sum, a few basics...

- Ask the questions as they are written. Do not 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.

The Washington Group

- City Group established by UN Statistical Commission in 2001
- Countries have ownership
 - national statistical offices of 133 countries and territories, 7 international organizations, 6 organizations that represent persons with disabilities
 - Emphasis on evidence and transparency – extensive testing of data collection tools in multiple countries

The New WG Website:

<http://www.washingtongroup-disability.com/>

