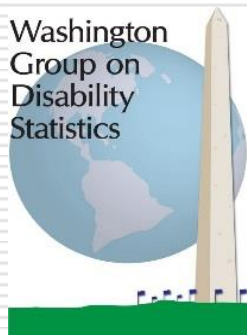


# Collecting Disability Data

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# The Challenge

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How to measure the broad experience of disability through:

- a limited number of questions,
  - a consistent manner,
  - a cross-culturally comparable way?
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# What works and what does not...

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# Even the best questions...

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## **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
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...will fail if a Screener is added

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Is the person *suffering* from any *disability* (or difficulty) in the carrying out everyday activities?

Resulting prevalence: 3.2%

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## ...or if Negative Wording is added

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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.

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# ...or if the Responses are changed

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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, a little / Yes, a lot / Cannot do

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

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# Administration Issues to Consider

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

- Translation
  - Cultural appropriateness
  - Comparable testing
  - Administration of questionnaire
  - Interviewer training
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# Adopting Existing Tools: Translation

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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
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# Adopting Existing Tools: Translation

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## Methods of translation:

- Literal: word-for-word  
(forward/back translation)
  - Non-literal: concept based  
(team translation)
  - Computer based: No!
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# Adopting Existing Tools: Translation

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## 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
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# Adopting Existing Tools: Translation

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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 sense of when to translate *literally* and when to *translate* conceptually

A competent translator is not only bilingual but bicultural.

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# Adopting Existing Tools: Cultural Appropriateness

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Careful review of existing content of questions.

- Ensure cultural relevance of concepts, skills or references
  - Avoid gender and other biases
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# Using Existing Tools: Translation

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Questions AND answer categories need to be carefully translated.

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# Example: Seeing

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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.
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# Example: Response options

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- 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.
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# Cognitive Testing of Translations

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- 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.

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# Interviewer Training/Instructions

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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).

# A few basics...

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- 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.
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# Discussion

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