

Data Production and Analysis Using the WG Tools



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

Monitoring the UN CRPD and SDGs through data disaggregation

- to describe disability data as a **continuum** of functioning based on graded responses to questions in the functional domains, and
- to define a **cut-off** (or a set of cut-offs) that can be agreed upon internationally in order to disaggregate outcome indicators (e.g. access to education, employment) by disability status
- Include the questions on disability in the data collections that produce the SDGs

This allows for the calculation of prevalence rates and disaggregation.

The Challenge

How to measure the broad experience of disability through:

- a limited number of questions,
- a consistent manner,
- 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.

Washington Group Approach to Disability Measurement

Identifying people who, because of a health condition, have **difficulties with basic, universal activities** that make them at greater **risk** than the general population for **limitations in participation** in an **unaccommodating environment**.

WG Short Set

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

Disability Identifiers – WG-SS

DISABILITY1: the level of inclusion is at least one domain is coded *some difficulty* or *a lot of difficulty* or *cannot do at all*.

DISABILITY2: the level of inclusion is at least 2 domains are coded *some difficulty* or any 1 domain is coded *a lot of difficulty* or *cannot do at all*.

DISABILITY3: the level of inclusion is any 1 domain is coded *a lot of difficulty* or *cannot do at all*.

This is the cut-off recommended by the WG.

DISABILITY4: the level of inclusion is any one domain is coded *cannot do at all*.

Disability Identifiers – WG-ES

WG-ES1: Complete Extended Set: 25 questions, 11 domains

WG-ES2: Modified Extended Set (WG-ES1 *minus* Pain and Fatigue): 20 questions, 9 domains

WG-ES3: Short Set Enhanced (WG-SS *plus* Upper body, Anxiety and Depression): 12 questions, 9 domains.

Disability Identifiers - CFM

Three levels of difficulty defined:

	Children age 2-4	Children age 5-17
Level 1: Mild to severe	<ul style="list-style-type: none"> At least 1 domain is some difficulty, a lot of difficulty or cannot do at all except Controlling behavior: coded more or a lot more 	<ul style="list-style-type: none"> At least 1 domain is some difficulty, a lot of difficulty or cannot do at all except Anxiety and Depression: coded weekly or daily
Level 2: Moderate to severe	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Controlling behavior: coded more or a lot more 	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Anxiety and Depression: coded daily
Level 3: Severe	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Anxiety and Depression: coded daily

Mainstreaming disability statistics: The Path to Disaggregation

- Identify which data collection systems will be used for monitoring population-based SDG indicators
- Include one of the Washington Group question sets in each of these data collection systems
- Once the questions become integrated into core statistical systems
 - Information on disability becomes available for use by all government agencies and civil society
 - Disaggregating outcomes (education, employment etc.) by disability status becomes routine and sustainable

WG-SS and Data Disaggregation

Disaggregation requirements

- Need a straightforward and simple way to identify persons with disabilities: the WG questions identify those at greater risk than the general population for limitations in participation.
- Need indicator/outcome data (education, employment, income, health care access) from data collections (census/surveys) that also include the above disability identifier.

There is no single disability prevalence

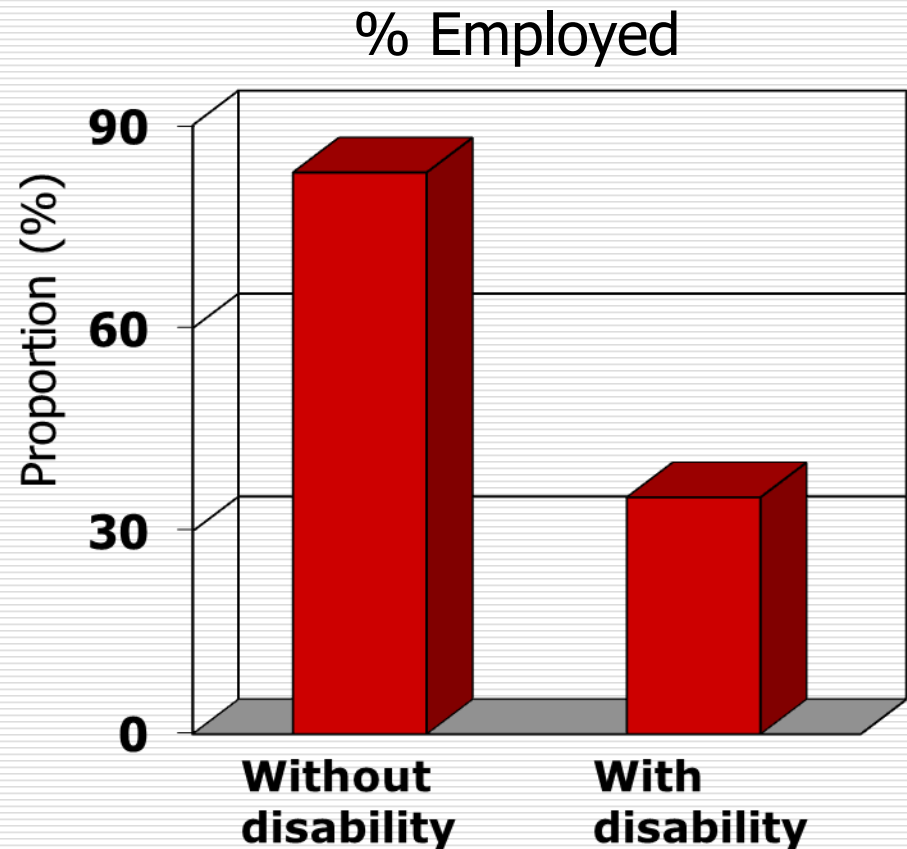
- Disability in a population is best described as a continuum of functioning, and the determination of the prevalence of disability will depend on where a cut-off is determined along that continuum.
- There is more than one possible cut-off.
- It becomes important therefore when describing disability in text or tables to clearly define which cut-off was chosen and reasons for making that choice.

Disability prevalence USA

Person with disability has:	n	%
at least 1 Domain is 'some difficulty'	7511	41.9
at least 2 Domains are 'some difficulty'	3672	19.6
at least 1 Domain is 'a lot of difficulty'	1872	9.5
at least 1 Domain is 'unable to do it'	465	2.2

Disaggregation by disability status

- Seeks to identify all those at greater risk than the general population for limitations in participation.
- Disability used as a **disaggregation variable**.



Disability by employment

Person with disability has at least:	Overall prevalence	% working	
		Without disability	With disability
1 Domain 'some difficulty'	35.4	76.6	60.2
2 Domains 'some difficulty'	14.9	74.6	48.5
1 Domain 'a lot of difficulty'	6.6	73.5	30.8
1 Domain 'unable to do it'	1.2	71.4	14.6

WG Recommendation:

For purposes of reporting and generating internationally comparable data, the WG has recommended the following cutoff be used to define the population of persons with disabilities:

- The sub-population identified as *with disability* includes those with *at least one domain* that is coded as *a lot of difficulty* or *cannot do it at all*.

Creating the WG disability dichotomy

- Responses to the 6 questions range from 1: no difficulty to 4: cannot do at all
- If responses at all 6 questions are 1 or 2 – i.e. the person has no difficulty or only some difficulty over the 6 domains, then the individual is considered as *without disability*.
- If any one (or more) of the 6 domain responses is 3: a lot of difficulty or 4: cannot do at all – then the person is considered as *with disability*.

Disaggregation in US NHIS data

NHIS 2013: <u>18-64 years of age</u> Weighted %	Disability status: WG Short set: <i>Cut-off is at least a lot of difficulty in at least 1 domain</i>	
	Without disability	With Disability
Employment Status Last Week=Working	73.4	29.1
Current every day smoker	14.5	27.8
Covered by health insurance? (Yes)	79.5	81.0

Monitoring the UN CRPD and SDGs through data disaggregation

WG question sets are developed

- to collect internationally comparable data based on the ICF model
- that fulfill the monitoring requirements established by the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals.

WG Aids and Tools

Guidelines and documentation:

- Conceptualization and Measurement of Disability (outlining WG Tools)
- WG Short Set Implementation Guidelines
- WG Short Set Question by Question Specifications
- Translation Protocol
- Interviewer Guidelines (under revision)
- Analytic Guidelines WG-SS and WG-ES-F including SPSS and SAS syntax
- Regional guide to improve disability data collection and analysis in Arab speaking countries (with ESCWA)
- WG-ES-F Question by Question Specifications (finalized)

The WG Blog

1. How are the Washington Group Questions Consistent with the Social Model of Disability?
2. Translating the Washington Group Short Set Questions
3. Washington Group Questions and the Sustainable Development Goals
4. How does the WG-SS Differ from Disability Eligibility Determination?
5. Everybody Counts: Putting the Washington Group Questions into Action
6. Does the WG-SS Identify all People with Disabilities, and Does it Matter?

The WG Blog

7. The Washington Group Questions in Action: Six Lessons Sightsavers has Learned so Far...
8. Cognitive Interviewing for the Washington Group
9. Using the Washington Group Questions to Monitor Inclusion of Persons with Disabilities in Nepal, Cameroon, India and Guatemala
10. Basic Guide to Sampling for Disability Surveys
11. Training on How to Ask “Disability” Questions on Censuses and Surveys
12. Should the Washington Group Questions Determine if Difficulties are Long-term or Short-term?

Frequently Asked Questions (FAQs)

FAQ: Can I change the introductory sentence?

- The introductory sentence: *"The next questions ask about difficulties you may have doing certain activities because of a health problem."* is included as a way of transitioning from one section of the questionnaire to another.
- Countries may choose not to use this introductory sentence, but...

it is important not to use the term 'disability' or other negative terminology in the questionnaire, when introducing the Short Set of questions – or at any point during training or data collection.

FAQ: How are the questions administered?

It is recommended that the response options 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 difficulty
- Yes, some difficulty
- Yes, a lot of difficulty
- Cannot do it at all

FAQ: On the use of assistive devices

The intention with the Short Set questions is to record, with the exception of seeing and hearing, difficulties people have with unaccommodated functioning, that is without the use of assistive devices or assistance.

FAQ: Temporary versus long-term difficulties?

- WG questions do not address the duration of difficulty.
- Testing has shown that people answering the WG SS most often think of their usual state.
- That is, 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 break has healed, they will return to their normal state.
- While some respondents may answer that they do have difficulty even if the difficulty is expected to be temporary, the WG does not consider this to be a problem in terms of data collection.

FAQ: Can I use the WG Short Set on children or adolescents?

- The domains covered by the WG questions are suitable for children five years and above.
- The questions will identify children with functional difficulties in the domains included, but will miss many children with developmental or psychosocial disabilities.
- The WG and UNICEF collaborated on a Child Functioning Module which is the preferred tool for collecting information on children.

FAQ: Can the Short Set be used as a diagnostic tool?

- The WG Short Set does not identify specific health conditions or diagnostic categories but rather captures the possible impact of these conditions on functional abilities.
- Additional questions can be added to a survey following the Short Set to obtain information on the cause of the functional difficulties.

FAQ: Does the WG-SS include all those with disability? (1)

- Beyond the 6 domains included in the WG-SS, other functional domains were considered: upper body functioning and affect [anxiety & depression].
- These were not included as they would require more than one question per domain and some domains, such as anxiety & depression, are not appropriate for a census.
- The WG-SS will not identify all persons with all types of difficulties in basic activities.

FAQ: Does the WG-SS include all those with disability? (2)

- However, evidence shows that using these questions covering major functional domains identifies the large majority of people with disabilities, and so is useful for making inferences about the characteristics of people with disabilities in the population and their outcomes that are critical for policy planning and evaluation.

FAQ: What about the absence of psycho-social functioning?

- The domains of functioning included in the WG-SS are not mutually exclusive – and those with anxiety or depression may also have difficulties with communication or self-care – and, while not explicitly identified, would be captured and included through these domains of functioning.
- To identify those with difficulties in psycho-social functioning, a more extensive set of questions is needed.
- The WG Extended Set on Functioning was designed in part to meet that need.

FAQ: How is the WG SS meant to be used?

- The **WG Short Set was not designed to be used in isolation.**
 - It should be used in conjunction with other measurement tools, i.e. *within* a larger survey to enable disaggregation of outcome measures (employment status, educational attainment, etc.) by disability status.
- It can be used in a census or survey format
- The focus on functioning and the brevity of the tool means that it can be rapidly and easily incorporated into a variety of settings.

FAQ: Can I modify the questions? (1)

- The WG recommends that the questions *not* be modified – but translated and used as written.
- Modifications, whether minor and major, can affect how the questions will function and could result in poor quality and non-comparable data.
- The answer categories should never be changed – and should, if necessary, be carefully translated!

FAQ: Can I modify the questions? (2)

- There are, however, a few exceptions to that rule:
 - Do you have difficulty hearing even if using a hearing aid?
 - *If hearing aids are nonexistent in your country, that clause can be omitted.*
 - Do you have difficulty hearing?
 - Do you have difficulty walking or climbing stairs?
 - *If a country doesn't have stairs, steps or ladders then that clause can be omitted.*
 - Do you have difficulty walking?

FAQ: 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’.

FAQ: 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.

FAQ: 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, 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.

FAQ: 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.

What works and what does not...

The WG-SS will fail if a Screener is added...

Do you have a *disability*?

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

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).

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.

'Disability' is complex, the WG SS questions are not.

- During enumerator training, it is important not to overburden interviewers with the complexity of the disability process.
- Conceptualizing disability may be seen as a complicated: the outcome of the interaction between a person with a functional limitation (difficulties doing basic functional activities) and an unaccommodating environment that results in the inability to fully participate in society. (UNCRPD)
- Measuring disability using the WG SS questions is simple and straight-forward.