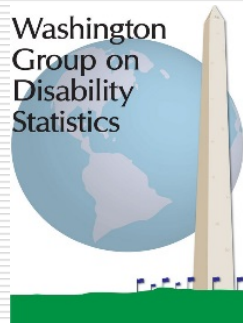# Implementing the WG SS

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

The Challenge

How to measure the broad experience of disability through:

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

What works and what does not…

Monitoring Adoption of the WG Short Set

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,
- actual question/response option wording, 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. Data collection years ranged from 2002 to 2013; however, the majority of data were collected during the 2010 census cycle.)

Results

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 (2011-2013)   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 out everyday activities?

Resulting 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 / Yes, a lot / Cannot do

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

Translation

Translation is required for existing tools to ensure:

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

Questions AND Answer categories need to be carefully translated

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

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

Recommended Method of Translation

Non-literal, concept based translation by consensus (Team translation)

- 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 undergoes a 'cognitive evaluation' and is pretested

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

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.

'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.

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 <u>unaccommodated</u> functioning, that is <u>without</u> 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 I change or adapt the questions to meet my needs?

- In order to collect internationally comparable data, **it is important that the WG questions be used without any changes to the wording**, order of questions, response categories, and cut-off points for classification of disability.

- There are very limited exceptions to this rule.

  - For example, in countries where hearing aids are not available, omitting the hearing aid clause is allowed.

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: 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.

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.

Mainstreaming disability statistics

- WG questions can be added to any on-going data collections;

  - Can be used in any national or subnational survey (health, labor force, income & expenditure, DHS, MICS etc.)

- Once the WG questions become integrated into core statistical systems – disaggregating outcomes (education, employment etc.) by disability status becomes routine

Data Production and Analysis Using the WG Tools

What can the WG SS produce?

Domain specific outputs:

- a range of functioning based on graded responses on each of the 6 domains

Overall outputs:

- a set of disability scores (based on different cut-offs) suitable for disaggregation

Prevalence (weighted %) by domain and degree of difficulty

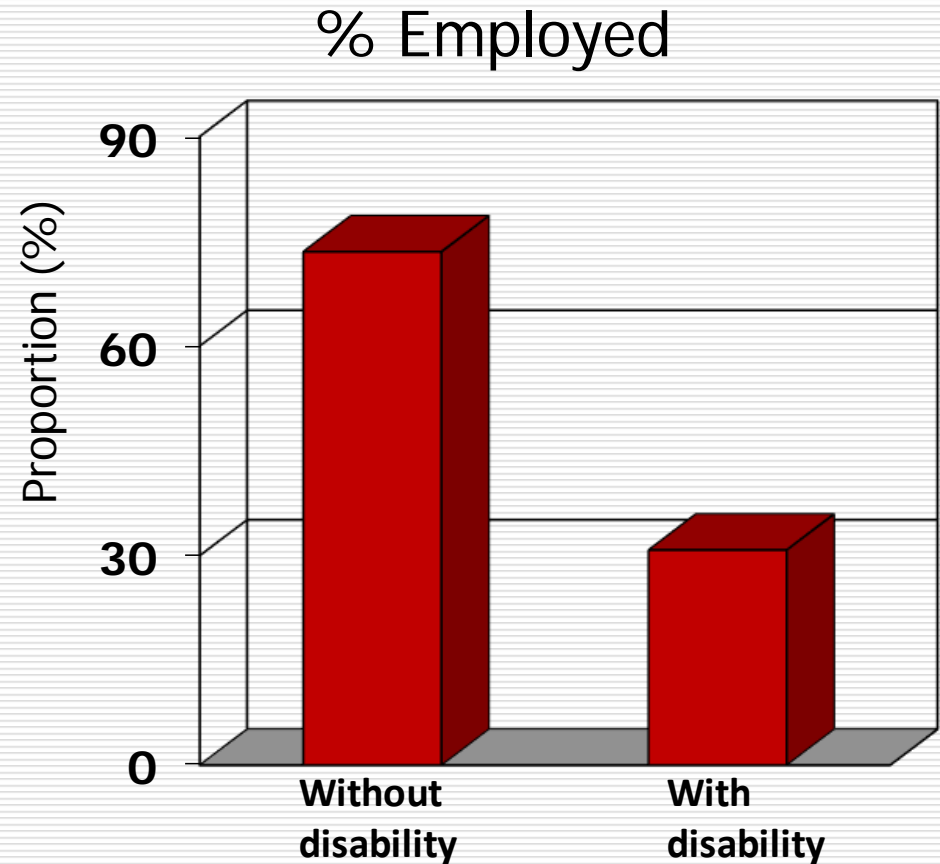| Core Domain	At least:		
	Some difficulty	A lot of difficulty	Unable To do it
Vision	17.1	2.0	0.2
Hearing	17.2	1.8	0.1
Mobility	17.0	5.7	1.8
Cognition	16.8	2.1	0.1
Self-Care	3.8	0.9	0.3
Communicating	4.8	0.7	0.2

Disaggregation requirements

- Need a straightforward and simple way to <u>identify persons with disabilities</u>: the WG questions identify those at greater risk than the general population for limitations in participation.

- Need <u>indicator/outcome data</u> (education, employment, income, health care access) from data collections (census/surveys) that also include the above disability identifier.

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.

% Employed

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.*

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

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.

Disaggregation in US NHIS data

NHIS 2013: 18-64 years of age Weighted %	Disability status: WG Short set: Cut-off is at least *a lot of difficulty* in at least 1 domain	
	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