Introduction to Disability Data Collection and the Washington Group Question Sets

Jennifer Madans
Why collect data on disability?

• To describe the functional status of the population

• To address whether persons with disability are being fully included in society as required by the UN Convention on the Rights of Persons with Disability and the 2030 Agenda on Sustainable Development and the Sustainable Development Goals (SDGs)
Objectives of the UNCRPD and the SDG’s - and Implications for Data

UN Convention on the Rights of Persons with Disability

**Goal:** Full participation of persons with disabilities

**Role of Data:** The information ... shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations ... to identify and address the barriers faced by persons with disabilities in exercising their rights.

2030 Agenda on Sustainable Development and the Sustainable Development Goals (SDGs)

**Goal:** No one left behind

**Role of Data:** Disaggregation of indicators
Have We Met the UNCRPD and SDG Objectives?

If bars are at equal height we have.

If bars are not at equal height we have not.
The information needed to create the figure and answer the question in the previous slide comes from censuses and surveys. So -

How we ask questions on surveys matters!
The ICF Model - 2001

Health Condition (disorder/disease)

Body Function & Structure (Impairment) → Activities (Limitation) ← Participation (Restriction)

Personal Factors

Environmental Factors

The Challenge

- It is not possible to write one question or a short set of survey questions that can adequately and accurately capture the complexity of disability in its entirety.

And yet,

- Survey questions must be short, clear, and precise.

As a result,

- Many problematic questions have been used.
Problematic Questions

Questions used to identify persons with disabilities in a Census:

1. Are you disabled in any way? Yes/No
2. What is your disability?
   - Blind Yes/No
   - Deaf / dumb Yes/No
   - Crippled Yes/No
   - Mentally retarded Yes/No

A medical model approach based on identifying and measuring impairments. The word disability is used in the question.
The Washington Group (WG)

• June 2001: UN International Seminar on the Measurement of Disability

• WG established as a City Group under the aegis of the UN Statistical Commission to:
  • address the need for population based measures of disability,
  • foster international cooperation in the area of health and disability statistics,
  • produce internationally tested measures to monitor status of persons with disability, and
  • incorporate disability into national statistical systems.
The Question Development Challenge

As illustrated in the ICF, disability is complex:

• incorporates a variety of different components: body functions & structure, limitations in activities (capacity) and restrictions in participation (performance), and

• includes characteristics of both the person and their environment.

As a result, the language of disability is not specific – the term means different things to different people including census respondents.

Finally, in some cultures, stigma is associated with disability – creating additional challenges to measurement and ultimately inclusion.
The Question Development Challenge

How to measure the broad experience of disability through:

• a limited number of questions,

• in a consistent manner,

• and in a cross-culturally comparable way?
The Solution

The WG developed an approach to measuring disability based on identifying those who:

• because of **difficulties** doing certain **universal, basic actions**,

• are at greater **risk** than the general population

• for **limitations in participation**.
The ICF Model - 2001

WG questions focus on identifying those with difficulties doing certain universal, basic actions.
Washington Group Objective

Develop a set of questions that:

• capture a *part of the disability complexity*

• can be used in a valid, reliable and internationally comparable manner.

The WG may only capture a *part of the social model of disability* but when:

• used in conjunction with other data collected in the census or survey (such as access to education or employment)

• the resulting analyses address the social model of disability.
Those Analyses Document Whether the UNCRPD and SDG Objectives Have Been Met

If bars are at equal height we have.
If bars are not at equal height we have not.
WG Short Set on Functioning (WG-SS)

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 steps?
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 difficulty; Some difficulty; A lot of difficulty; Cannot do at all
WG Short Set Objectives

• Identify persons with similar types and degree of limitations in basic actions regardless of nationality or culture;
• Represent the majority *(but not all)* persons with limitations in basic actions; and
• Represent commonly occurring limitations in domains that can be captured in the census context.
Intended Use of the Data

• Compare levels of participation in employment, education, or family life for those *with* disability versus those *without* disability to see if persons with disability have achieved social inclusion.

• Monitor effectiveness of programs and policies to promote full participation.

• Monitor prevalence trends for persons with limitations in specific basic action domains.
Advantages

• Functional approach
  • Tested successfully in many countries (low, middle, and high income)

• Designed to be internationally comparable

• Identifies most people with disabilities

• Can easily be added to existing censuses and surveys or to project based data
  • Approximately 1.25 minutes to administer.
Limitations of WG-SS

• Not appropriate for children under age 5, and misses some children with developmental issues age 5-18
• Misses those with psychosocial issues that do not affect communication, cognition or self-care
• Does not capture age of onset
• Does not directly capture environmental barriers
• Does not address functioning with and without assistive devices
WG Questions Adopted Widely

- Used in censuses or surveys in over 80 countries.
- Has been promoted by international aid programs, (DFID/UK and DFAT/Australia), as the means to collect disability data in all programs and projects.
- Has been introduced as the means for collecting disability data by the UN Statistical Division (UNSD) and the UN Economic Commission for Europe for the 2020 round of censuses.
- Adopted as the way to disaggregate data for the Incheon Strategy on Making the Right Real in Asia.
- Recommended by UN DESA’s Disability Data Experts Group as way of disaggregating the SDGs by disability status.
Filling the Gaps: Other WG Tools Completed

- **WG Extended Set on Functioning (WG-ES)** includes 37 questions over 11 domains and is intended to:
  - get at psychosocial issues, and
  - begin to get at the use of assistive devices.

- **WG-SS Enhanced Set** is a reduced version of the WG-ES and includes the 6 WG-SS domains plus 2 questions on upper body functioning and 4 questions on affect (2 on anxiety and 2 on depression).

- **UNICEF/WG Child Functioning Module (CFM)** in 2 parts:
  - for children age 2-4 and children 5-17 years of age;
  - includes domains specific to child functioning and development

- **ILO/WG Labor Force Survey Disability Module (LFS-DM)**
  - includes the WG-SS plus (optionally) 2 affect questions
  - addresses environmental facilitators and barriers to employment
Filling the Gaps: Other WG Tools Currently Under Development/Testing

• UNICEF/WG Child Functioning Module – Teacher Version
• UNICEF/WG Inclusive Educational Module
  • Addresses environmental facilitators and barriers to education for ALL children
• WG Module on Psychosocial Functioning and Mental Health
Data Production and Analysis Using the WG Tools

Mitchell Loeb
WG Short Set on Functioning (WG-SS)

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** steps?
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 difficulty; Some difficulty; A lot of difficulty; Cannot do at all
What Can the WG-SS Produce?

Domain specific outputs:
• a range of estimates of functioning based on graded responses on each of the 6 domains

Overall outputs:
• a set of disability status indicators (based on different cut-offs) suitable for disaggregation
• a discrete gradation of severity or disability severity indicator (none/mild/moderate/severe)
Prevalence (weighted %) of Degree of Difficulty by Domain

<table>
<thead>
<tr>
<th>Core Domain</th>
<th>Some difficulty</th>
<th>A lot of difficulty</th>
<th>Unable To do it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td>17.1</td>
<td>2.0</td>
<td>0.2</td>
</tr>
<tr>
<td>Hearing</td>
<td>17.2</td>
<td>1.8</td>
<td>0.1</td>
</tr>
<tr>
<td>Mobility</td>
<td>17.0</td>
<td>5.7</td>
<td>1.8</td>
</tr>
<tr>
<td>Cognition</td>
<td>16.8</td>
<td>2.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Self-Care</td>
<td>3.8</td>
<td>0.9</td>
<td>0.3</td>
</tr>
<tr>
<td>Communicating</td>
<td>4.8</td>
<td>0.7</td>
<td>0.2</td>
</tr>
</tbody>
</table>
Deaf-Blind Analysis

In addition to providing information on single domains, it is possible to provide information on two or more domains as in this example which combines responses from the seeing and hearing domains to identify those who are deaf and blind.
### Cross-tabulation: Difficulty Seeing by Difficulty Hearing

<table>
<thead>
<tr>
<th>HEAR_SS: Difficulty Hearing</th>
<th>VIS_SS: Difficulty Seeing</th>
<th>DK*</th>
<th>None</th>
<th>Some</th>
<th>A lot</th>
<th>Unable</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>DK*</td>
<td>4</td>
<td>6</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3</td>
<td>11734</td>
<td>1735</td>
<td>187</td>
<td>21</td>
<td>13680</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>3</td>
<td>1772</td>
<td>869</td>
<td>102</td>
<td>7</td>
<td>2753</td>
<td></td>
</tr>
<tr>
<td>A lot</td>
<td>0</td>
<td>167</td>
<td>99</td>
<td>42</td>
<td>2</td>
<td>310</td>
<td></td>
</tr>
<tr>
<td>Unable</td>
<td>0</td>
<td>11</td>
<td>5</td>
<td>1</td>
<td>6</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>10</strong></td>
<td><strong>13690</strong></td>
<td><strong>2708</strong></td>
<td><strong>333</strong></td>
<td><strong>36</strong></td>
<td><strong>16777</strong></td>
<td></td>
</tr>
</tbody>
</table>

*Refused/Not ascertained/Don’t know
Prevalence of Deaf-Blind using Different Definitions

Of 16,777 individuals 18 years and older:

• **51** or **0.3%** had *a lot* or *cannot do* on BOTH vision and hearing;

• **add** those with *a lot* or *cannot do* on one and *at least some* on the other (**213**), the prevalence is **1.5%**;

• **add** those with *at least some* on BOTH (**869**), the prevalence is **6.8%**.
Defining a Disability Continuum and a Disability Dichotomy

The WG questions fulfill two specific data needs:

• to describe disability as a continuum of functioning from no difficulty to some difficulty, a lot of difficulty and unable to do at all, and

• to define a cut-off (or a set of cut-offs) that can be agreed upon internationally in order to disaggregate other information (e.g. access to education, employment) by disability status
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**.

Participation measure is compared by disability status.
Possible WG-SS Disability Identifiers as Labeled in Analytic Syntax

**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 Prevalence in USA using Different Definitions of Disability

<table>
<thead>
<tr>
<th>Person with disability has:</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>at least 1 Domain is ‘some difficulty’</td>
<td>7511</td>
<td>41.9</td>
</tr>
<tr>
<td>at least 2 Domains are ‘some difficulty’</td>
<td>3672</td>
<td>19.6</td>
</tr>
<tr>
<td>at least 1 Domain is ‘a lot of difficulty’</td>
<td>1872</td>
<td>9.5</td>
</tr>
<tr>
<td>at least 1 Domain is ‘unable to do it’</td>
<td>465</td>
<td>2.2</td>
</tr>
</tbody>
</table>
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*. 
So, Who has a Disability?

<table>
<thead>
<tr>
<th>Vision</th>
<th>Hearing</th>
<th>Mobility</th>
<th>Cognition</th>
<th>Self-care</th>
<th>Communication</th>
<th>Disability?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
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<td>No</td>
<td>A lot</td>
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<td>Unable</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td>No</td>
<td>Unable</td>
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<td>A lot</td>
<td>A lot</td>
<td>No</td>
<td>Unable</td>
<td>Yes</td>
</tr>
</tbody>
</table>
...and What about Missing Data?

<table>
<thead>
<tr>
<th>Vision</th>
<th>Hearing</th>
<th>Mobility</th>
<th>Cognition</th>
<th>Self-care</th>
<th>Communication</th>
<th>Disability?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable</td>
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<td>Yes</td>
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</tbody>
</table>
Syntax to Create Disability Indicators is Available in SPSS, SAS, Stata and CSPro

WG-SS, WG-SS Enhanced and WG-ES:
• SPSS / SAS / Stata / CSPro
• http://www.washingtongroup-disability.com/publications/implementing/

CFM:
• SPSS / Stata
• https://data.unicef.org/resources/module-child-functioning-tabulation-plan-narrative/
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**.

Participation measure is compared by disability status

![Bar chart showing % Employed: Without disability vs With disability](chart.png)
Defining the Population with Disability for Disaggregation

<table>
<thead>
<tr>
<th>SDG Indicator</th>
<th>Disability Status:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>WG Short Set</td>
</tr>
<tr>
<td></td>
<td>Cut-off = at least</td>
</tr>
<tr>
<td></td>
<td>a lot of difficulty</td>
</tr>
<tr>
<td></td>
<td>in at least 1 domain</td>
</tr>
<tr>
<td>Employment Status Last Week: % working</td>
<td>Without disability</td>
</tr>
<tr>
<td></td>
<td>With disability</td>
</tr>
<tr>
<td>Current Every Day Smoker</td>
<td>14.5</td>
</tr>
<tr>
<td></td>
<td>27.8</td>
</tr>
<tr>
<td>Health Insurance Coverage (yes)</td>
<td>79.5</td>
</tr>
<tr>
<td></td>
<td>81.0</td>
</tr>
</tbody>
</table>

Source: NHIS 2013; n=13404; ages 18-64
A Reminder: Where the Cut-off is Set, Matters when Evaluating Full Inclusion!

| 1 Domain ‘some difficulty’ | 14.9 | 74.6 | 48.5 |
| 2 Domains ‘some difficulty’ | 35.4 | 76.6 | 60.2 |
| 1 Domain ‘a lot of difficulty’ | 6.6 | 73.5 | 30.8 |
| 1 Domain ‘unable to do it’ | 1.2 | 71.4 | 14.6 |

Source: NHIS 2013; n=13404; ages 18-64
Other Disability Measures

Discrete measures of severity: none, mild, moderate and severe difficulty

Counting the number of domains of difficulty per person

Most severe domain (single or multiple)
Standardized Approach to Monitoring

• By standardizing disability data collection instruments it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures;

• Data can be used to assess a country’s compliance with development goals and the UN Convention on the Rights of Persons with Disabilities and, over time, improvement in meeting these goals.
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:
  • Core information on disability becomes available for use by all government agencies and civil society; and
  • Disaggregating outcomes (education, employment etc.) by disability status becomes routine and sustainable.
Best Practices for Interviewing and Data Collection

Jennifer Madans
Administration Issues to Consider

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

• Administration of questionnaire
• Translation & Cultural appropriateness
• Enumerator training
Administration of Questionnaire

• Question specifications are provided for each of the six WG-SS questions.

• Specifications are also provided for the answer categories

• These specifications should be used for question administration and for translation
DO YOU HAVE DIFFICULTY SEEING, EVEN IF WEARING GLASSES?

Purpose: identify persons who have vision difficulties or problems seeing even when wearing glasses (if they wear glasses).

Seeing refers to:
- using eyes and visual capacity
- in order to perceive or observe what is happening

Even when wearing glasses refers to:
- difficulty seeing with glasses if the respondent has, and uses, them
- NOT how vision would be if glasses, or better glasses, were provided or available.
Seeing: continued

Included are problems:

• seeing things close up or far away, and
• seeing out of one eye or only seeing directly in front but not to the sides.
• Not limited to problems with the eyes, problems seeing can be related to other body functions such as the effects of a stroke

Any problem with vision that the respondent considers a problem should be captured.
**Question Specifications: Hearing**

**DO YOU HAVE DIFFICULTY HEARING, EVEN IF USING A HEARING AID?**

Purpose: to identify persons who have some hearing limitation or problems of any kind with their hearing even when using a hearing aid (if they wear a hearing aid).

Hearing refers to:
- using ears and auditory (or hearing) capacity
- in order to know what is being said or the sounds of activity, including danger

*Even if using a hearing aid* refers to:
- difficulty hearing with a hearing aid if the respondent has, and uses, that device
- NOT how hearing would be if hearing aids, or better hearing aids, were provided or available.
Hearing: continued

Included are problems:

• hearing in a noisy or a quiet environment,
• distinguishing sounds from different sources, and
• hearing in one ear or both ears.

• Not limited to problems with the ears, problems hearing can be related to other body functions

Any difficulty with hearing that is considered a problem should be captured.
Question specifications: Mobility

DO YOU HAVE DIFFICULTY WALKING OR CLIMBING STEPS?

Purpose: identify persons who have some *limitation or problems of any kind getting around on foot*.

Walking refers to:
- the use of lower limbs (legs) in such a way as to propel oneself over the ground to get from point A to point B
- *without assistance of any device* (wheelchair, crutches, walker etc.) or human. If such assistance is needed, the person has difficulty walking.

Included are problems:
- walking short (about 100 yards/meters) or long distances (about 500 yards/meters),
- walking any distance without stopping to rest is included, and
- walking up or down steps.
Mobility: continued

Difficulties walking can include those resulting from:
• Musculoskeletal system problems or loss of limbs
• Impairments in balance
• Endurance
• Other non-musculoskeletal systems, for example blind people having difficulty walking in an unfamiliar place or deaf people having difficulty climbing stairs when there is no lighting.

Any difficulty with walking (whether it is on flat land or up or down steps) that is considered a problem should be captured.
Question Specifications: Cognition

DO YOU HAVE DIFFICULTY REMEMBERING OR CONCENTRATING?

Purpose: to identify persons who have some problems with remembering or focusing attention that contribute to difficulty in doing their daily activities.

Remembering refers to:
• the use of memory to recall incidents or events and bring to mind or think again about something that has taken place in the past (either the recent past or further back)
• With younger people, often associated with storing facts learned in school and being able to retrieve them when needed.
• NOT be equated with memorizing or with good or bad memories.

Concentrating refers to:
• the use of mental ability to accomplish some task such as reading, calculating numbers, learning something
• associated with focusing on the task at hand in order to complete the task.
Cognition: continued

Included are problems:

• finding one’s way around, being unable to concentrate on an activity, or forgetting one’s whereabouts or the date, and

• problems remembering what someone just said or becoming confused or frightened about most things.

Any difficulty with remembering, concentrating or understanding what is going on around them that they or family members (if the family member is the respondent) consider a problem should be captured.

Note: difficulties remembering or concentrating because of common everyday situations such as high workload or stress, or as a result of substance abuse are EXCLUDED.
Question specifications: Self-care

DO YOU HAVE DIFFICULTY WASHING ALL OVER OR DRESSING?

Purpose: to identify persons who have some problems with taking care of themselves independently

Washing all over refers to:
• the process of cleaning one’s entire body (usually with soap and water) in the usual manner for the culture
• including cleaning hair and feet

Dressing refers to:
• all aspects of putting clothing or garments on the upper and lower body including the feet if culturally appropriate.
Self-care: continued

Included are:

• acts of gathering clothing from storage areas (i.e. closet, dressers), securing buttons, tying knots, zipping, etc.

• gathering any necessary items for bathing such as soap or shampoo, a wash cloth, or water

Washing and dressing represent tasks that occur on a daily basis and are considered basic, universal activities.
Question Specifications: Communication

**USING YOUR USUAL LANGUAGE, DO YOU HAVE DIFFICULTY COMMUNICATING**
(for example understanding or being understood by others)?

Purpose: to identify persons who have some problems with talking, listening or understanding speech such that it contributes to difficulty in making themselves understood to others or understanding others.

Communicating refers to:

• exchanging information or ideas with other people through the use of language.

Communication difficulties can originate in numerous places in the exchange process:

• Mechanical problems such as hearing impairment or speech impairment
• Problems cognitively interpreting the sounds that the auditory system is gathering
• Inability to recognize the words that are being used
• Inability to compose a sentence or say a word even when the person knows the word and sentence.
Communication: continued

Included are:

• the use of the voice for the exchange or using signs (including sign language) or writing the information to be conveyed.
• problems making oneself understood, or problems understanding other people when they speak or try to communicate in other ways.

NOTE: Difficulty understanding or being understood due to non-native or unfamiliar language is NOT included.
Response Options

No difficulty - Some difficulty - A lot of difficulty - Cannot do at all

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.

The response categories that divide the continuum into approximately 3 equal pieces so as to capture the maximum amount of variation in functioning.
Translation Objectives

When translation is required, it is important to ensure:

- Question constructs are adequately captured
- Cultural appropriateness

Translation and cultural appropriateness are closely related. If a question written in the source language uses words or terms that are foreign to the target language and culture, steps should be taken to address this situation. (See validation and cognitive testing later in this lesson.)

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

- Reduces differences in question interpretation
- Increases reliability and validity of data collected
Things that Translators Must Consider:

• Will respondents understand this translated question? Is the type of language appropriate for the intended audience?
• Are the nuances of the original question text maintained in the translation?
• Does the wording of the question feel natural?
• Are the response choices likely to be understood and used as in the original question?
Translation Methods

Forward/Backward translation: this is a literal, word-for-word approach to translation

TRAPD method (recommended): this is a non-literal, concept-based approach that is based on team translation and consensus. Involves: Translation, Review, Adjudication, Pretesting and Documentation.

Computer based, like Google Translate: Never
Both questions AND answer categories need to be carefully translated

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*.

Translators must select descriptors that divides the continuum into approximately 3 equal pieces so as to capture the maximum amount of variation in functioning. This is depicted in the next slide.
Visualizations of Translations

**A correct translation:**

No difficulty          Some difficulty      A lot of difficulty        Cannot do at all

With disability

**A poor translation:**

No difficulty                Moderate           Severe      Cannot do at all

With disability
Validation of the Translation

When the translation is complete, it should be cognitively tested
• to ensure comparability to the source language, and
• to fix any problems with translated versions of the questions.

The goal of cognitive testing of new translations is to assess whether the translated version of the survey questions accurately captures the intent of the question and the answer categories as in the original source language version.

This testing of a translated questionnaire should not be overlooked.
Cognitive testing will...

• Uncover translation mistakes and expressions that might be unnatural in the target language.

• Uncover regional variation in terms since languages are sometimes spoken in different varieties (dialects/colloquialisms) depending on regional differences.

• Uncover any lack of familiarity with terms used or the use of culturally unknown or irrelevant concepts.

• Uncover questions that are complex and cognitively difficult to understand and answer. In general, it is best to keep questions (in both source and target languages) as simple and concise as possible.
If there is no approved translation

Avoid translating ‘on the fly’

An alternative to a approved translation is for the enumerators in areas where the same languages are spoken to:

• Come together to form a small team
• To discuss and agree upon a common translation that all could use using the best practices described for translation in general
• Test the translations to the extent possible
• This will reduce variability among enumerators and improve overall data quality.

If this is not possible, enumerators should follow best translation practices in developing their own translations
Enumerator Training

Mitchell Loeb
Enumerator Training & Instructions

Standard census processes include:
• Careful selection of enumerators, and
• Thorough training in basic question/response techniques

Questions on functioning/disability require some specific training.

Guidelines for conducting data collection in the field should follow standard enumerator practices.

This is important for ALL questions – but particularly important for questions on disability.

These guidelines are normally well established within the National Statistical Office.
Standard Administration (1 of 2)

A standard interview administration means that every enumerator must conduct the interview the same way with each respondent.

This is done to minimize differences in responses that might occur if formatting conventions or interviewing techniques are changed with every respondent.
Standard Administration (2 of 2)

The enumerator’s manner, such as a rushed interview or lack of interest may greatly affect responses.

Research has shown that the enumerator can have an effect on the data collection because of four factors: socioeconomic background, unconventional administration of the questionnaire, wording and intonation, and reaction to respondent’s difficulties in understanding the questionnaire.

Except for the enumerator’s background, the other three factors can be addressed in training.
Role of the Enumerator (1 of 2)

The enumerator is responsible for asking questions, answering the respondent’s queries and recording answers following standard interviewing procedures.

The enumerator must ensure that the respondent understands the questions by using interviewing techniques, such as neutral probes, clarification and appropriate feedback, and determining whether the answer given is appropriate.

Listening to what the respondent is communicating, both verbally and non-verbally, will ensure that the information is correct.
Role of the Enumerator (2 of 2)

The enumerator must also set the pace of the interview and keep the respondent focused and interested. The atmosphere should be comfortable and pleasant at all times.

Before going to the field, the enumerator must know both the content of the questionnaire as well as how the questionnaire is to be administered.

A thorough preparation, as well as extensive practice, will guarantee that this is achieved.
Ask the questions as they are written and ask all questions

Generally part of standard enumerator instruction but particularly important for functioning/disability questions

Minor variations in question wording can lead to a significant response variation, that is, responses that do not meet the intent of the question particularly for question on functioning/disability

Enumerators should not in any way tell the respondent that the questions are about disability or use the term disability.

Do not change the order of the questions.
Respondent must answer all questions (1 of 2)

Don’t assume a response by observation.

The enumerator may be tempted to skip questions or make comments such as “I know this probably doesn’t apply to you, but...”. This should never be done.

An enumerator may be asking questions of a person who is in a wheelchair and might feel awkward asking this person if they have difficulty walking. It might seem simplest to just mark the response ‘cannot do at all’. This should not be done.
Respondent must answer all questions (2 of 2)

While a wheelchair does offer mobility assistance, it doesn’t preclude that the person cannot walk at all. They may be able to walk short distances without problem.

If the response to a question seems obvious and the enumerator feels uncomfortable asking it, they might say:

“I need to ask all questions to every respondent to verify all information.”

If questions seem repetitive, the enumerator might say:

“You told me that before…but I still need to ask you this question as it is written”. 
Practice interviews before going into the field (1)

Prepare!

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

It is recommended that enumerators are very familiar with the contents of the survey before they go into the field. They should make eye contact with the respondent and be able to conduct the interview smoothly in a conversational manner.
Practice interviews before going into the field (2)

Enumerators bring their own conceptions about the sensitivity of questions to the process.

Enumerators bring their own conceptions about disability to the process.

If the trainer is uncomfortable, then the enumerator will be uncomfortable.

If the enumerator is uncomfortable, then the respondent will be so too.
Practice interviews before going into the field (3)

To guard against enumerator error, training should reinforce that:

- the functioning questions should be treated like any other question.
- they should not be regarded as sensitive
- the term disability should not be used
- The enumerators need to be familiar and comfortable with the material

Following standard enumerator training practices, enumerators should be well versed in the contents of the survey before they go into the field. They should make eye contact with the respondent and be able to conduct the interview smoothly in a conversational manner.
Additional Resources


ALSO: additional tips and guidance can be found from UNICEF: https://data.unicef.org/resources/module-on-child-functioning-manual-for-interviewers/
Resources Available
Guidelines and Documentation:

- Data Collection Tools Developed by the WG (Conceptualization and Measurement of Disability)
- WG Short Set Implementation Guidelines (Includes some FAQs and Do’s & Don’ts)
- Question Specifications for the WG-SS, WG-SS Enhanced, WG-ES and CFM
- Translation Protocol
- Guidelines for Cognitive Testing of Translated Questionnaires
Guidelines and Documentation:

• Analytic Guidelines for the WG-SS, WG-SS Enhanced and WG-ES including fully annotated syntax in SPSS, SAS, Stata and CSPro

• Regional Guide to Improve Disability Data Collection and Analysis in Arabic-speaking Countries (with ESCWA)

• Interviewer Guidelines for use of the WG Tools

• Additional Documentation and Analytic Guidelines for the CFM (available currently through UNICEF link)
Examples of some Frequently Asked Questions (FAQs)

1. What is the purpose of the introductory statement?
2. How should the questions be administered?
3. What about short-term or temporary difficulties? Are they included?
4. Do the questions refer to the use of assistive devices?
5. Can the Short Set be answered by a proxy respondent?
6. Does the Short Set apply to all age groups?
7. Where is the best place to add the Short Set to a census or survey?
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


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?
For more information about the WG visit our new website: http://www.washingtongroup-disability.com/

Questions: WG_Secretariat@cdc.gov