The Washington Group on Disability Statistics: Interviewer Guidelines

I. Introduction

The question sets developed by the Washington Group on Disability Statistics (WG) are intended to be embedded in other ongoing data collections. This might be a census or a survey, for example a Labor Force Survey (LFS), Household Income and Expenditure Survey (HIES), Demographic and Health Survey (DHS), or Living Standard Measurement Study (LSMS). These guidelines focus specifically on the WG modules and are intended to accompany the guidelines already developed for these ongoing surveys. Standard interviewing best practices will apply.

WG modules include the Short Set on Functioning (WG-SS), Short Set Enhanced (WG-SS Enhanced), Extended Set on Functioning (WG-ES), and the WG/UNICEF Child Functioning Module (CFM). A Manual for Interviewers using the CFM is also available on the UNICEF website:
https://data.unicef.org/resources/module-on-child-functioning-manual-for-interviewers/.

The guidelines provided in this document should be used in conjunction with both the relevant questionnaire and the question specifications for the WG module being used. Interviewers should use these question specifications when respondents request clarification about specific questions, or terminology, and should refrain from offering their own interpretations.

The question sets can be accessed here:
WG-SS: https://www.wg.lldev.co.uk/question-sets/wg-short-set-on-functioning-wg-ss/
WG-SS Enhanced: https://www.wg.lldev.co.uk/question-sets/wg-short-set-on-functioning-%e2%80%93-enhanced-wg-ss-enhanced/
WG-ES: https://www.wg.lldev.co.uk/question-sets/wg-extended-set-on-functioning-wg-es/
CFM: https://www.wg.lldev.co.uk/question-sets/wgunicef-child-functioning-module-cfm/

Question specifications for each module are available here:
WG-SS:
https://www.wg.lldev.co.uk/fileadmin/uploads/wg/Documents/Questions/WG_Implementation_Document__4A_-_WG-SS_Question_Specifications.pdf

The **Washington Group Implementation Documents** cover the tools developed by the Washington Group on Disability Statistics (WG) to collect internationally comparable disability data on censuses and surveys. The documents address best practices in implementing the Short Set, Extended Set, Short Set – Enhanced, the WG / UNICEF Child Functioning Modules for children 2-4 and 5-17 years of age, and the WG / ILO LFS Disability Module, as well as other WG tools. Topics include translation, question specifications, analytic guidelines, programming code for analyses, the use of the tools for the purposes of disaggregation, and more.

To locate other WG Implementation Documents and more information, visit the Washington Group website: http://www.washingtongroup-disability.com/.

WG-SS Enhanced:
https://www.wg.lldev.co.uk/fileadmin/uploads/wg/Documents/Questions/WG_Implementation_Document__4C_-_WG-SS_Enhanced_Question_Specifications.pdf
WG-ES:
https://www.wg.lldev.co.uk/fileadmin/uploads/wg/Documents/Questions/WG_Implementation_Document__4B_-_WG-ES_Question_Specifications.pdf
CFM: [Currently available on UNICEF webpage] https://data.unicef.org/resources/module-on-child-functioning-manual-for-interviewers/

1.1 Overview and Objectives

Disability is a complex concept, involving aspects of body function and structure (impairments), capacity (measured as the ability to carry out basic activities without the benefit of any assistance or accommodation), and performance (measured as the individual's ability to carry out these same basic activities using available assistive technologies and assistance and available environmental accommodations). Disability emerges from the interaction of the person and their environment. For persons with functional difficulty, disability occurs when barriers are met in the environment, resulting in an individual being prevented from participating in society to the same extent as an individual without any functional difficulties. For example, a person in a wheelchair who has difficulty walking becomes disabled in a non-accommodating environment, such as lack of ramps to access buildings or lifts to access public transportation. Given appropriate accommodations, however, those with similar mobility difficulties would be better able to participate in the same activities (accessing school or public buildings) as those without these difficulties.

The WG questions focus on the presence and extent of functional difficulties rather than the causes of those difficulties. For example, a mobility limitation can be the result of cerebral palsy, loss of limbs, paralysis, muscular dystrophy, significant cardio-vascular conditions, or spinal cord injuries. Moreover, those with the same cause of difficulties (e.g., medical diagnosis) may have very different types or degrees of limitations. Rather than ask about causes, the WG questions ask about difficulties. In addition, functioning occurs on a continuum of difficulty from very mild to very severe. The WG questions have a scaled response set rather than a dichotomous yes/no response set. For example, one child might have a slight speech impairment but can easily be understood, while another child might not be able to speak at all thus making communication very challenging – even when their difficulties are caused by the same condition (e.g., cerebral palsy). Some of these difficulties and associated conditions are traditionally seen as a "disability" while others are not.

The WG modules are designed to capture this continuum of functional abilities across a breadth of domains. This approach allows for flexibility in analyzing the data. During data analysis, responses to individual questions can be combined to develop estimates of the number of persons at risk of participation limitations due to functional difficulties across all domains and degrees of difficulty. The questions are designed to be included on a population-based survey to produce an estimate of the number of persons at risk. They are not intended as a diagnostic tool or as a means to determine eligibility for social benefits.

In summary, each module developed by the WG, whether used in a census or survey, will identify those with difficulties in basic universal domains of functioning that, in the absence of an accommodating

environment, would place that individual at greater risk than the general population of experiencing limited or restricted participation in society.

'Disability' is measured through questions that focus on functioning – and difficulties in carrying out specific activities. That is, 'disability' is inferred and not measured directly through a question like: Do you have a disability?

'Disability' *can be* a sensitive topic to ask about in data collection, and moreover not all people understand the term 'disability' in the same way. Therefore, rather than ask directly using the term 'disability', the questions developed by the WG do not use that term. Interviewers are therefore trained and encouraged to avoid using the term 'disability' when introducing or asking the questions.

1.2 Respondents

Depending on the census or survey in which the WG questions are embedded, the respondent may be the head of a household who is familiar with all household members, or the selected individual(s) within the households themselves, that is, the person who will be asked about their own level of functioning. Respondents do not need to be literate, although, depending on age, maturity and cognitive ability, respondents may find some questions or concepts more difficult to understand than others. When a respondent cannot answer questions for any of the reasons listed above, a proxy respondent for that person can be interviewed. This would apply to all questions in the census or survey and not just the questions on disability.

These guidelines, and the WG question specifications, will assist interviewers in both becoming more familiar with the WG modules for interviewing and data collection and becoming more at ease with interviewing respondents who have disability. The latter also applies to interviewing persons with disability about topics other than disability.

1.3 Translations

Prior to beginning the data collection, ensure that there is a version of the questions in the local language. All translation should be done before the survey is fielded. Translation by the interviewer at the time of the interview – that is, during the actual interview or "on the fly" – should be avoided since small differences in interpretation of a phrase or even a single word can greatly reduce the reliability and validity of the data. In countries where there are many local languages and resources are not available for 'official' translations into all local languages, the WG suggests that teams of interviewers from those specific localities or regions get together before data collection to agree, amongst themselves and with supervision, on a local language version that can be used consistently in the field.

If the survey has been translated from English into a local language, it should be determined that the intended concepts from the English version are captured in the translation (cognitively tested) prior to going into the field. This may involve more than a simple word for word translation of the question (even if checked by "back translation"). The translated question should be cognitively tested to ensure that the intended meaning of each question is easily understood in the colloquial language of the respondents.

Instructions for the translation of WG questions and the cognitive testing of the translated version(s) can be found here: https://www.wg.lldev.co.uk/implementation/translation-guidelines/

II. General Interviewing Guidelines for WG Question Sets

2.1 Standard Administration

A standard interview administration means that every interviewer 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. Respondents might answer very differently if the question wording in an interview is changed or asked in different ways. Similarly, the environment in which the interview is conducted will impact the quality of data collected, such as if the interview is conducted while other people are in the room. Likewise, the interviewer's manner, such as a rushed interview or lack of interest may greatly affect responses. Research has shown that the interviewer 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 interviewer's background, the other three factors can be addressed in training.

2.2 Role of the Interviewer

The interviewer is responsible for asking questions, answering the respondent's queries and recording answers following all interviewing procedures used in the parent survey (that is, the survey into which the WG questions are embedded). The interviewer 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. The interviewer 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 interviewer must know the 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.

2.3 Questionnaire Conventions

The questions use three standard typographical conventions to indicate how the survey questions should be read to the respondent

a. Anything written in standard print is to be read to the respondent.

   Example:
   [Do/Does] [you/he/she] have difficulty walking or climbing steps?

b. Anything written in [*italics*] is an interviewer instruction and should not be read aloud

   Example:
   [*If child does NOT wear glasses*]
   Does [name] have difficulty seeing? Would you say… [*Read response categories*]
      1) No difficulty
      2) Some difficulty

3) A lot of difficulty
4) Cannot do at all

c. Insert the appropriate words (a respondent's name or a pronoun) wherever indicated by brackets, such as [name].

Examples:
Does [name] wear glasses?
[Do/Does] [you/he/she] have difficulty walking or climbing steps?

2.4 Interviewer Instructions

Interviewers should follow closely the conventions already in place for the census or survey into which the WG questions have been added. Some general instructions are worth repeating and a few instructions specific to the WG modules should be followed. These are outlined below:

a. **Know the questionnaire thoroughly** before going into the field for data collection. The best interviews are those that are 'conversational' – meaning that the interviewer makes eye contact with the respondent and the interview progresses as a guided conversation rather a series of formal and stiff questions and answers.

b. **Introducing the disability questions in a way that uses neutral language**.
Most of the modules developed by the WG offer an introductory statement that is used in the census or survey context to transition from one topic to another. If the WG module is preceded by a question on, say, the environment or education, the introductory statement would prepare the respondent for questions on a different topic, as well as focus the respondent on difficulties they may have that relate to physical or mental health. Use of the introductory statement may not be needed in all situations, especially if including the statement may interrupt the flow of question administration. Examples of introductory statements used are:

- The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.
- The next questions ask about difficulties you may have in doing certain activities.
- Now I am going to ask you some questions about your ability to do different activities.

An introductory statement is not always necessary; however, if it is appropriate and included in the country's census or survey, then it should be used.

NOTE: The word "disability" is not used to introduce the WG questions, nor anywhere else in the question sets.

c. **Do not ask a screening question.** The respondent must be asked all questions in the module for each person in the sample. The interviewer MUST NOT first ask if anyone in the household has a disability and then administer the questionnaire only to those individuals. Nor should the interviewer assume that someone does or does not have a disability simply by observing them. The goal of the questionnaire is to identify a range of functional difficulties even those that the

respondent or the interviewer may not consider a "disability" or that may not be visible to the interviewer.

d. **Ask the questions exactly as written.** Minor variations in question wording can lead to a significant response variation, that is, responses that do not meet the intent of the question.

Standard rules in interviewing should be followed to avoid biased answers and to ensure comparability of data.
- Read questions as they are written in the text and do not change the wording (that is, do not paraphrase or rephrase).
- Do not skip questions even if the respondent has given the answer earlier or if one answer applies to questions that are similar.
- Do not change the order of the questions.
- Response options must be read aloud to the respondent, except for Don't know (DK), Refuse, Not Applicable (NA) and other.

The interviewer should never assume what the respondent will say because of their health condition or lifestyle. The interviewer 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. For example, it should not be assumed that someone sitting in a wheelchair cannot walk at all. The individual may be able to walk short distances or even longer distances with the aid of a walker or cane or another person's assistance.

If the response to a question seems obvious and the interviewer 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 interviewer might say:
   "You told me that before…but I still need to ask you this question as it is written".

e. **Follow the skip-patterns carefully.** The survey directs the interviewer to skip certain questions based on a respondent's responses.

III. Good Practices in Interviewing Persons with Disability in Any Survey

This section is intended to broaden understanding of disability. It outlines general points on communicating with persons with disabilities and provides information to assist in interviewing persons with different types of disability. It may even help in interviewing respondents in general – regardless of their disability status. However, it must be stressed that just as no two respondents in general are alike, neither are no two persons with disabilities alike, even if they have the same condition or impairment. The same condition may have a major effect on one person but a minor effect on another. Furthermore, while there are occasions when disability does severely affect the ability of a person to participate in an interview, most people with a disability can fully participate in an interview and effectively speak for themselves.

3.1 What is Disability?

As noted in a previous section, disability is difficult to describe in one or two sentences, partly because it is complex, covering a range of elements: body function and structure (impairments), activity limitations, participation restrictions and elements of both the person (age, sex, etc.) and their environment (both the physical and nonphysical).

Disability is likely to affect everyone at some stage in their lives. Generally, disability is regarded as the combination of the elements listed above: a reduced ability to perform one or more basic, universal activities (e.g. difficulty seeing, hearing, walking etc.) that, in an unaccommodating environment, would put that person at risk of reduced social participation (in things like education or employment, civic engagement or leisure activities).

For example, someone might have paralysis in their legs (impairment) which affects their ability to walk (activity) which, when encountering barriers in the environment, might limit their ability to find employment (participation).

While it is important to recognize the role of the environment in understanding disability, in common speech, 'disability' is often used as being synonymous with limitation in basic functional activities. The term *disability* will be used in this way in the material that follows.

Disability is not a specific medical diagnosis such as spinal cord injury, cerebral palsy, or autism. While this information is often important in a medical context, learning this information is not the purpose of the question sets developed by the WG.

3.2 Meeting People with Disability

There are several important points on this topic:
- Meeting people with disabilities is no different from meeting anyone else. It is simply a matter of using common courtesy when interacting with people of all abilities.
- People with disabilities, like everyone else, have the right to say no, to decline to answer any question, or to exit the interview whenever they want. Participation in an interview is voluntary.
- People with a disability want to be treated in the same way as people who do not have a disability. They should not be treated as special or incapable of participating in the interview.
- When interviewing a person with disability, especially if another person is present during the interview (for example, a sign language interpreter or a family member), be sure to address the

question to the person with disability, and not to the interpreter or the person facilitating the interview.
- Do not be embarrassed about using common expressions, such as "see you later" (to someone with seeing difficulty) or "I'll be running along now" (to someone with mobility difficulty). They use these terms themselves.
- Always relate to the person with respect, dignity, empathy and equality.

3.3 Tips on Interviewing People with Certain Kinds of Disabilities

a. Interviewing People with Hearing Disabilities

The following is recommended:
- Face the person at all times when speaking. Do not cover your mouth or rest your chin on your hand when speaking. Do not turn away from the person when speaking - stop speaking when you turn to look at a screen or get information.
- Make sure you have the person's attention before you start speaking, using visual cues.
- Ensure that only one person is speaking at a time.
- If difficulties occur when you are speaking directly to a deaf person, you may want to use written notes or let them see the questions on the questionnaire.
- Do not assume the person can lip read. Even if the individual can lip read, it is never wholly reliable. Only about 25% of words are visible on the lips, so you will have to check that you have got your message across.
- If the person is lip reading, you should:
    - Make sure you are facing the light and that your lips are visible (keep hands, etc. away from your mouth)
    - Speak slowly and clearly, at a steady rhythm. Shouting does not help and may in fact make it more difficult to understand.
    - Use facial expressions and gestures that emphasize the words you use.
- If an interpreter is present, speak directly to the deaf person. The interpreter will sign the conversation between you.

b. Interviewing People with Physical Disabilities

The following is recommended:
- If you are talking to someone in a wheelchair try to put your head at the same level.
- Do not push a wheelchair without asking the person first.
- Never address the escort or personal assistant, instead of the person with a disability, always talk to the person.
- Remember that first impressions are often deceiving. New and stressful situations may increase muscle stiffness and decrease individual's control and dexterity.

c. Interviewing People Who Are Blind or Partially Sighted

The following is recommended:
- When you approach a person who is blind, remember to identify yourself clearly and indicate anyone else who is present. For example, "Hello, Mr. Clarke. I am John Murphy and I have Pat Casey with me". You can touch them lightly on the arm to indicate you are addressing them.

- Do not leave someone talking to an empty space. Let the person know when you wish to end the interview or move away.

d. Interviewing People with Communication Disabilities

The following is recommended:
- Be encouraging and patient. Do not correct or speak for the person. Wait until the person finishes and resist the temptation to finish sentences.
- If you do not understand, do not pretend. Repeat as much as you do understand and use the person's reactions to guide you. Ask them to tell you again, if necessary.

e. Interviewing People with Cognitive, Learning or Intellectual Disabilities

The following is recommended:
- You may need to repeat terms or words more than once. If necessary, offer to show them the questionnaire. A person with cognitive, learning or intellectual disabilities may have difficulty understanding what you are saying.
- Listen carefully to what the person is saying, not how it is said.
- Depending on the nature of the condition, people with difficulty understanding you may require assistance in participating in and completing the interview, that is, they may require a proxy (friend or relative) to respond for them or to assist them in responding. Always follow standard survey practices for proxy interviews.

f. Interviewing People with Emotional or Mental Health Disabilities

The following is recommended:
- If needed, it may be necessary to keep the interview focused and short. If necessary, arrange to come back at a later time or date to complete the questionnaire. Persons with emotional or mental health disabilities may have difficulty with concentration and stamina.
- Establish a good relationship and give the individual plenty of encouragement and support.
- Be patient as sometimes people with mental health difficulties may be withdrawn or disruptive because they have not understood a question, or experience frustration in trying to answer the question or make themselves understood.
- If necessary, the interviewer may suggest a break in the interview.
- Make allowances for stressful events. Interviewers should be patient and flexible with respect to the time allotted for the interview.