

This first in a series of **Washington Group Implementation Documents** will cover the Short Set of questions for censuses and surveys. The document will provide a brief history of the development of the Short Set, introduce the module and provide answers to some Frequently Asked Questions on the application and use of the module. Guidelines and restrictions related to modifying the Short Set are also included.

Further Implementation Documents will cover: Translation and Short Set question specifications; Interviewer Guidelines; Analysis Guidelines; and other tools developed by the WG and partners for the measurement of disability (e.g. WG Extended Set, UNICEF/WG Child Functioning Module).

The Washington Group Short Set on Functioning

The Short Set of six questions on functioning for use on national censuses and surveys was developed, tested and adopted by the Washington Group on Disability Statistics (WG). The questions reflect advances in the conceptualization of disability and use the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) as a conceptual framework.

In a break from the past and the medicalization of disability that placed disability within the person and characterized it by impairments or deficits in bodily functions, the ICF presents a bio-psychosocial model that locates disability as at the interaction between a person's capabilities (limitation in functioning) and environmental barriers (physical, social, cultural or legislative) that may limit their participation in society. The WG Short Set of questions used the ICF as a framework, focusing on the component of activity, or functioning, limitations.

Rationale for Choice of Questions

Rather than a dichotomous (Yes/No) static state, disability is a dynamic, complex process that must be understood and 'unraveled' in order to create a measurement tool that would have international relevance and could produce cross-nationally comparable data.

The complexity of the concept has resulted in the proliferation of statistics on disability that are neither comparable nor easy to interpret. Furthermore, disability data are collected for different purposes such as to estimate population prevalence or the need for providing certain services. Each purpose will elicit a different statistic and even when the intention is to measure the same concept, the actual questions used will differ in ways that severely limit comparability. The conclusion is not that some estimates are right and others are wrong, but that they are measuring different things.

The WG chose to develop questions that would address the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life. A major reason for this choice is the pivotal importance of the issue of social participation and equal rights from a policy perspective as illustrated by the UN Convention on the Rights of Persons with Disabilities and the requirements established in the 2030 Agenda on Sustainable Development.

To that end, the WG focused on measuring difficulty functioning in 6 basic, universal actions (capabilities) that, in an unaccommodating environment would place an individual at risk of restricted

social participation. The measurement of environmental barriers and participation (e.g. access to education or employment) are extramural; the task then is in data analysis to determine whether persons identified with difficulties or limitations in these basic actions have participation rates equal to those without limitations.

The WG questions were designed to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources. While the ideal would be to collect information on all aspects of the disablement process as depicted in the ICF (impairments, activity limitations, participation restrictions and environmental barriers and facilitators) and to identify every person with a disability within every community, this would not be possible given the limited number of questions that can be asked on a national census and in most surveys. The basic actions represented in this set of 6 questions are those that are most often found to limit an individual and result in participation restrictions. Domains were selected using the criteria of simplicity, brevity, universality and comparability. The information that results from the use of these questions will, a) represent the majority of, but not all, persons with limitation in basic actions, b) represent the most commonly occurring limitations in basic actions, and c) be able to capture persons with similar problems across countries.

The Short Set on Functioning

The set is comprised of questions on six core functional domains: seeing, hearing, walking, cognition, self-care, and communication:

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?¹
2. Do you have difficulty hearing, even if using a hearing aid?¹
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)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. The response categories capture the full spectrum of functioning from mild to severe.

Question testing and validation

The development of the Short Set of questions began with a review of existing disability questions, including, for example the questions that were used in Censuses. Based on the results of cognitive testing, individual questions were either modified or abandoned. None of these existing question sets fulfilled, in full, the needs and requirements of the WG.

¹ The inclusion of assistive devices was considered for two domains only, seeing and hearing, as limitations in these domains can often be overcome with the use of glasses or hearing aids. See FAQ below.

Multiple rounds of cognitive testing of questions proposed for the Short Set were carried out in 2006 in fifteen countries: Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Philippines, Uganda, Mexico, Tanzania, Vietnam, Argentina, Brazil, and Paraguay. An overview of cognitive testing results can be found here: Miller K et al. Results of a cross-national structured cognitive interviewing protocol to test measures of disability. *Quality & Quantity*, 2011; **45(4)**:801–815.

Some Frequently Asked Questions (FAQ)²

What is the purpose of the introductory statement?

The introductory statement (The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM) was included for the purpose of transitioning from topic to topic in a census context. The census format includes a small number of questions on different topics with topics changing quickly. The purpose of the introductory statement was to inform the respondent that the next set of questions had a health context. For example, if these questions followed a series of questions on another subject, sanitation, for example, the introductory statement would provide a transition to more health-related subject matter. In a larger survey, where this module might follow other health-related questions, and where the context is already established, the introductory statement could be dropped if the flow of the questionnaire is not adversely affected.

How should the questions be 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:

- 1) No, no difficulty
- 2) Yes, some difficulty
- 3) Yes, a lot of difficulty
- 4) Cannot do it at all.

Respondents may become familiar with the answer categories after the first few questions. In this case, the recommendation to repeat the categories can be relaxed. This is most likely to occur when the questions are asked of multiple people in a household. If respondents provide responses using the required answer categories, the categories do not need to be repeated after every questions. They should be repeated as soon as the respondent does not use the required category (e.g., responds ‘yes’) or after the 3rd or 4th question. Enumerators will require training in when it is appropriate to not read the answer categories.

What about short-term or temporary difficulties? Are they included?

The WG questions do not address duration. Based on test results, the WG determined that when people answer the short set of questions, more often than not, they think of the difficulties they have in 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 soon after the bone has mended, they will return to their normal state. Some respondents may answer that they do have difficulty walking even if the difficulty is expected to be temporary. The WG does not consider this to be a problem. At any given point in time there will be a portion of the population that has some temporary difficulty with one or more of the domains covered in the short set. Individuals who answer in this way are also temporarily at risk of participation restrictions and in need of accommodations.

² Additional FAQ on WG tools can be found on the website, here: <http://www.washingtongroup-disability.com/frequently-asked-questions/>

There are hidden but significant costs to identifying those with only long-term difficulties. These include: 1) making incorrect assumptions about recovery; i.e. not all those with temporary difficulties will make a complete recovery and would, therefore, benefit from inclusion; and 2) the ability to identify the population that would benefit from universal design; i.e. even those with temporary difficulties will benefit, for the duration of their reduced functional capacity, from accommodations that reduce barriers to participation.

Modifying the questions to direct the respondent to only respond in terms of their usual functioning or to include temporary difficulties involves adding in a long, complex introductory statement. Respondents seldom listen to all of the instructions when survey modules are preceded with such long and wordy opening statements. For example, beginning a series of questions with the following instructions is often counterproductive:

The next questions ask about difficulties you may have doing certain activities only because of your HEALTH.

Please think about the last 30 days taking both good and bad days into account. Only consider difficulties that have lasted or are expected to last for 6 months or more.

Now thinking only about your health I want you to answer these questions WITHOUT taking into account any help.

A respondent has to think of, and remember, all those instructions when answering the questions that follow. Cognitive testing has shown that they do not always take these considerations into account when they respond. Respondents may focus on the instructions at the beginning of the statement or at the end, but they do not recall or consider all, or at times, any of the instructions.

For the reasons discussed above, the WG determined that measurement error (incorrect identification of a functional difficulty) was minimized by not reference to long term difficulties in the questions.

Do the questions refer to 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 (without the use of assistive devices or assistance).

The WG wants to be able to identify difficulties in functioning that may put a person at risk of limited or restricted participation. That risk of restricted participation – in the absence of accommodations – is ‘disability’ as defined by the UN Convention on the Rights of Persons with Disability (CRPD).

The domains of seeing and hearing are handled differently. In many cultures, both glasses/lenses and, to a lesser extent, hearing aids are ubiquitous and in most cases the use of these devices, especially glasses, is able to correct the difficulty almost completely. For this reason they are considered ‘within the skin’ or a part of the person. If, for example, the WG were to ask about difficulty seeing without the use of glasses, the resultant prevalence would be extremely high and would not identify a population at risk of participation restriction. However, in places where glasses or hearing aids are not common, the clause ‘even when wearing glasses’ can be omitted.

Can the Short Set be answered by a proxy respondent?

Ideally, the questions should be answered by the individual in question (self-report) with the exception of those who are not capable of responding themselves. However, in a census setting and for some types of surveys, it is common to have a primary respondent report for all other household members and this is acceptable in these context. In self-report situations, no one should be excluded because they cannot respond on their own (for example due to difficulty hearing, communicating, or an intellectual disability). The choice of a proxy respondent can be important and should be carefully considered before embarking upon the survey interview.

Does the Short Set apply to all age groups?

The six WG questions were designed for a census context (general population 5 years of age and above) where the collection of disability data in a country may be otherwise very limited. The WG has acknowledged that disability among children, due to the circumstances of child development and transition from infancy through adolescence, is not adequately covered by these questions and disability prevalence using the WG Short Set among those 5 – 17 years of age will be underestimated. However, in the absence of other measures and other data collection exercises, these questions will provide an indication of child functioning in the domains covered for the population 5 – 17 years of age.

Where is the best place to add the Short Set to a census or survey?

This module of six questions is best situated either at the beginning of a survey questionnaire (together with the demographic information collected on household family members) or towards the beginning of a section that deals with health information. It is recommended that the module not be added on at the end of the questionnaire.

Modifications to the WG Short Set of Questions: Possible Dos and Definite Don'ts

The implementation of the WG Short Set in many countries has begun to produce cross-nationally comparable data. Issues may arise as country NSOs begin the process of incorporating the questions into ongoing censuses or surveys including translation, use of a screener, the number of questions to include, and the categorical response options. Modifications to the original set of six questions, whether minor and major, can affect how the questions will function and could result in poor quality and non-comparable data. Below is a guide to modifications that should not be made and modifications that can be considered. These recommendations are based on testing that has been done by the Washington Group and by partners. Those wishing to make modifications not mentioned below should contact the Washington Group Secretariat for assistance. In many cases, suggested modifications have been tested and found to have negative effects.

1. Definite Don't: Avoid the use of the word “disability” both in the questionnaire and in the training of interviewers.

‘Disability’ is a word whose meaning can vary not only across cultures but among people in the same culture. Moreover, in some cultures the term is associated with shame and/or stigma. In order to avoid casting the questions in a negative frame or light and to reduce response variability due to differential understanding of the term, more neutral language needs to be used. In addition, rather than ask directly about disability per se, the focus of the questions is on functioning. The domains of functioning covered are both basic and universal; they are common to all countries and cultures and evidence has shown that they are recognized by people in different languages. The use of the term disability in the questionnaire

or in interaction between the interviewer/enumerator and the respondent will reintroduce variability in how the term is understood including introducing stigma and can reduce or eliminate the validity of the questions set.

2. Definite Don't: Do not use a screener

Evidence shows that single screener questions do not adequately identify the population of interest. Most screeners are of the form "Do you have a disability?" with yes/no answer categories. As noted above, the use of the term disability has very negative effects. Questions of this type identify only a portion of those experiencing functional problems. They equate disability with a medical problem (disability lies within the person) and by forcing a respondent to make a choice between affirming disability which in some cultures is associated with stigma and discrimination. Some screeners do not use the term disability but ask about medical conditions. While respondents can describe their difficulty doing activities, they often cannot report on their conditions. For example, respondents may not be aware of their conditions due to lack of medical care. The search for a one or two question screener that will identify the population of interest and results in no false negatives has been universally unsuccessful. The WG-SS represent the fewest number of questions that can be used to identify the population with disabilities. See also #4 below.

3. Possible Do: Changes to the clause: "...even if wearing glasses" and "even if using a hearing aid"

In a few countries we have learned that hearing aids are non-existent. In these cases it would be appropriate to omit the clause "...even if using a hearing aid."

On the other hand, to indiscriminately omit the clause "...even if wearing glasses." would grossly inflate disability prevalence since anyone who uses glasses or lenses to correct a visual impairment would answer affirmatively (many with serious difficulties). Only in places where glasses are close to non-existent should the clause be removed.

If time and space permit, it may be preferable to split the two sensory questions, as in the Extended Set:

Do you wear glasses?

1. Yes
2. No

If Yes: Do you have difficulty seeing even if wearing your glasses?

If No: Do you have difficulty seeing?

4. Possible Do: Asking a subset of the six questions

A comprehensive measure to determine disability would include all six domains of functioning: seeing, hearing, walking/climbing steps, remembering/concentrating, self-care and communication.

As noted in the 3rd revision of the Principles and Recommendations for Population and Housing Censuses (UNSD: <https://unstats.un.org/unsd/statcom/doc15/BG-Censuses.pdf>) four domains of functioning: seeing, hearing, walking/climbing steps, and remembering/concentrating are considered the most essential in determining disability status from census data in a way that would allow for international comparison. In circumstances where it is impossible for reasons of time or space to ask all six questions, these four domains should be included as the essential minimum.

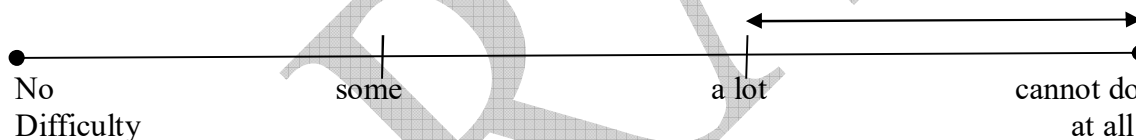
Furthermore, it has come to our attention that for reasons related to culture, in certain countries enumerators have had difficulty asking the self-care question. In such circumstances, the omission of this question is permissible.

To illustrate the net effect of asking six versus four questions, data from the 2013 US National Health Interview Survey (NHIS) show that disability prevalence among those 18 years and older (weighted) using all six Short Set questions is: 9.5%. Omitting the questions on self-care and communication reduces the prevalence to: 9.3%. Disability is not a uniquely unidimensional or single domain phenomenon. Among those with functioning difficulties (over six domains) in the 2013 NHIS sample, 27% have multiple difficulties. It could further be demonstrated that 92% of those with self-care difficulties and 78% of those with communication difficulties were included among those identified as having difficulties in the other 4 domains of functioning (that is, they were not explicitly excluded but omitting the question makes it impossible to estimate the population with this type of functional difficulty and to look at the impact on participation).

5. Definite Don't: Changing answer categories

Disability is not a Yes/No dichotomy but describes a dynamic and complex relationship between a person, the environment in which they live and their ability to participate in society on an equal basis with others. The aspects of functioning that are captured by the six questions are also not dichotomies; functioning in each of these domains exists on a continuum.

A question with a Yes/No response option forces the person answering to self-identify as having the difficulty or not. It is better to offer a range of responses as in the WG questions. The 4 answer categories recommended by the WG describe a continuum of functioning from no difficulty to Cannot do at all. The continuum can be visualized like this:



The distribution above creates four points equally distributed among the continuum that allows respondents to easily discriminate among options. The recommended cut-off (at *a lot of difficulty*) identifies those with the intended level of difficulties.

6. Possible Do: Modification to question administration.

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:

- 1) No, no difficulty
- 2) Yes, some difficulty
- 3) Yes, a lot of difficulty
- 4) Cannot do it at all.

If the 6 questions are asked of multiple persons in the household, the answer categories do not need to be repeated for each question once the respondent becomes familiar with them and responds using the

appropriate terminology; however, it is generally useful to repeat the answer categories every 3 or 4 questions.

The DHS (Demographic and Health Surveys) has recently adopted a disability module that operationalizes the WG short set of questions. In order to maintain consistency with other DHS modules and the format of the DHS in general, a modification was implemented in the *administration* of the questions – not the *content*. Rather than the formulation recommended by the WG above, the DHS uses the following formulation:

I would like to know if (NAME) has difficulty walking or climbing steps. Would you say that (NAME) has no difficulty walking or climbing steps, some difficulty, a lot of difficulty, or cannot walk or climb steps at all?

Both the content of the question and the response options remain the same. This is essential in producing comparable disability statistics cross-nationally. The possible effects of this modification are being evaluated.

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