An Introduction to the
Washington Group on Disability Statistics Question Sets

I.   A Short History on the Question Sets Developed by the Washington Group

In 2001, the **International Seminar on the Measurement of Disability**[1] was held in New York. During this meeting participants agreed that existing data on disability, especially in low- and middle-income countries, were scarce and often of poor quality. The participants further recognized there was need for common definitions, concepts, standards and methodologies in statistics about persons with disability, as well as a need for internationally comparable, high- quality disability data collection. The Seminar recommended the development of standard indicators using population-based measures of disability for country use and for international comparisons.

To address this urgent need, the Washington Group on Disability Statistics (WG) was formed as a **United Nations Statistical Commission City Group**. The main purpose of the WG is the promotion and coordination of international cooperation in generating statistics on disability suitable for censuses and national surveys. Its major objective is to provide basic information on disability that is comparable worldwide.

Since 2001 the WG has developed, extensively tested, and validated several tools for the collection of internationally comparable disability statistics. The WG meets annually with representatives from national statistical offices, UN agencies, and non-governmental organizations. In the past 20 years, over 135 countries have participated in the WG.

At the first meeting, members developed a work plan to guide the group's efforts. The first priority was the development and validation of a short set of questions primarily for use in national censuses but also suitable for use in surveys. The purpose of the **Short Set on Functioning**[2] (WG-SS), comprised of six questions on functioning in core domains, is to disaggregate the population by disability status in order to judge if persons with disability are participating equally in all aspects of society. To date, over 80 countries have used the WG-SS in censuses or surveys.

The next step was to develop an **Extended Set on Functioning** (WG-ES) for the adult population for use in surveys to capture more extensive information on functional status and other aspects of disability. The WG-ES has 37 questions (three of which are optional), too long for some censuses and surveys but short enough to be used regularly in a range of other data collection efforts.

There was also need for an intermediate-length question set, and in response to this need, the **Short Set on Functioning - Enhanced** (WG-SS Enhanced) was developed and validated. The Enhanced Short Set

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[1] **Blue text** – see page 8 VIII. Helpful References and Links – External
[2] **Red text** – see page 8 VIII. Helpful References and Links - Internal

uses the six Short Set questions plus an additional six questions drawn from the Extended Set (four questions about psychosocial functioning and two questions on upper body functioning).

While the WG-SS, WG-ES and WG-SS Enhanced are all useful for adult populations, questions were needed for the child population. In response, the **Child Functioning Module** (CFM) was developed by the WG in collaboration with **UNICEF**. There are two CFM versions – one for children aged 2-4 and a second for children aged 5-17, each containing functioning questions specifically relevant for that age group.

In the past several years, the WG has collaborated on additional tools. There is now a **Labor Force Survey Disability Module** (LFS-DM) developed by the WG in collaboration with the UN's International Labor Organization (ILO). Currently the WG is also working with UNICEF on an Inclusive Education Module.

Since its adoption in 2006, the WG-SS has been:
- (i) recommended by the United Nations Statistical Division (UNSD) (see: Principles and Recommendations for Population and Housing Censuses (rev. 3)) and the United Nations Economic Commission for Europe (UNECE) Council of European Statisticians as the preferred method for collecting information on disability in the current 2020 round of censuses,
- (ii) used in censuses or surveys in over 80 countries,
- (iii) promoted by international aid programs DFID (Department for International Development, UK) and DFAT (Department of Foreign Affairs and Trade, Australia) to collect disability data in all programs and projects,
- (iv) included in the DHS (Demographic and Health Surveys) of USAID (the United States Agency for International Development), currently in about 70 UNICEF-sponsored MICS (Multiple Indicator Cluster Surveys), and in about 70 World Bank-sponsored LSMS (Living Standards Measurement Study),
- (v) promoted as the means to determine disability status in humanitarian settings, and
- (vi) endorsed by a **Disability Data Expert Group** under the auspices of the **United Nations Department of Economic and Social Affairs** as the means to disaggregate the **2030 Agenda for Sustainable Development Goals** by disability status.

The WG-SS has been used by: (i) UN agencies: UNSD, OHCHR, UNICEF, ILO, UNFPA, UNESCO, UNHCR, UNDP, UN-Women, UNPRPD, World Bank, WHO and the Special Rapporteur on the rights of persons with disabilities, (ii) International NGOs: Humanity & Inclusion, Sightsavers, CBM, and (iii) academia.

II. Purpose for Identifying People with Disability

There are two main purposes for collecting data on disability through censuses and household surveys. The first is to estimate the prevalence of disability, and the second is to measure the extent of exclusion.

Prevalence

Using a census or survey to determine who has a disability is more complicated than just asking respondents a yes/no question such as, "Do you have a disability?" Functioning and disability are not

inherently dichotomies but exist along a continuum. An individual may have no functional difficulties, or just minor difficulties, or may have a lot of difficulty, and some are unable to carry out the function. For example, many people in a community can have difficulty walking but fewer people may have severe difficulties. When the difficulty reaches a point where it puts a person at risk of limiting their ability to participate in society, he or she is considered to have a disability. The point at which a difficulty becomes a disability, however, will vary. For some purposes, even having a little difficulty would be considered a disability where for others, disability would be defined by having a lot of difficulty. As a result, there is not one estimate of disability prevalence in a country or population group. There can, in fact, be many depending on the questions being asked and the level of difficulty chosen as the determination of disability. This topic will be explored further when the definition best suited for international comparisons is discussed.

Prevalence tells us how many people have a disability. This is important for understanding the scale of potential policy needs and impacts. Beyond simply knowing the aggregate number, it is also important to look at patterns of prevalence. That is, do the rates of disability differ by age, gender, geographical region, ethnicity, and other important socioeconomic factors? This can also direct policymakers to focus on specific policy interventions, as well as how and where resources may need to be allocated.

Measuring Exclusion

In generating data to understand how people with disability are faring, it is important always to compare how they are doing in relation to their peers without disability. If there are statistical differences in the number of people with disability in school or work, marrying or voting, then we can begin to discuss 'exclusion.' Therefore, the first step in measuring exclusion is to disaggregate outcome indicators to uncover any gaps between people with disability and their non-disabled family, friends and neighbors. Disaggregation enables the comparison of outcome measures between people with and without a disability. For example, if children with disability have a lower school attendance rate than children without disability, this is evidence of exclusion.

This approach is consistent with the key principle of the 2030 Agenda for Sustainable Development Goals (SDGs), namely the global eradication of disadvantage through the improvement of situations for all peoples. This is summarized in the concept of "leave no one behind". To know if groups of people are being left behind, it is important to compare progress achieved in SDG indicators in the general population with that of vulnerable groups. A country as a whole can be making progress on an indicator – for example, poverty eradication – but that does not necessarily mean all groups within that country are achieving progress, let alone equally.

For this reason, the introductory section of the SDGs notes the importance of disaggregating data by characteristics associated with exclusion and vulnerability, including disability. To disaggregate data it is necessary to include a disability indicator, such as the one derived from the WG questions, and the outcome indicator (e.g., the SDG indicator) in the same data collection activity. The SDG framework provides guidance on how to construct the SDG indicators. Fortunately, the WG-SS provides a high-quality, low-cost, easily implemented, and internationally comparable tool for identifying most people with disability.

Another way of examining exclusion is by monitoring program participation. That is, are people with disability being served on an equal basis? One example of the WG-SS being used for this purpose was

by Sightsavers in the administration of their programs. By asking the WG-SS at intake they discovered that women with disability were receiving services at a lower rate than men with disability and non-disabled men and women, suggesting there were disability and gender barriers leading to the exclusion of women with disability.

III. Criteria for Identifying People with Disability

The Washington Group Short Set on Functioning assesses whether the respondent has a disability based on responses to questions that assess difficulties with six universal basic activities (functions) – seeing, hearing, walking, self-care, cognition and communication. The questions do not ask a respondent to identify as having a 'disability.' Rather, an individual's answers to the six questions are used to define whether that person is 'with disability' or 'without disability' where disability is generally understood to mean at greater risk for limitations in participation. Respondents who answer 'a lot of difficulty' or 'cannot do it at all' to *at least one* of the six functioning questions should be considered a person with disability for the purpose of data disaggregation, particularly for the SDGs. These are people whose functional limitations place them at risk of being excluded if faced with physical, informational, attitudinal, or institutional barriers in their surrounding environment.

This approach is based upon the social model of disability which lies at the heart of the **UN Convention on the Rights of Persons with Disabilities (UNCRPD)**. The social model was groundbreaking in its view of people with disability. The model distinguishes between an impairment (e.g., a problem of body structure such as a person's inability to move their legs) and a disability. Disability is the result of the interaction of the impairment and the surrounding environment (e.g., unable to move her legs, this woman has not been able to attend school, marry or be hired for a job because of a non-accommodating environment). In other words, disability is not the same as an impairment but emerges through the interaction of a person's functional ability (which results from problems with body structure and function) and their environment. People are not excluded in society because they cannot move their legs. Rather, they are excluded because they live in an inaccessible environment without access to assistive devices and often also face discrimination.

The Washington Group Questions are used to document the relationship between functional limitations and inclusion by identifying if there are differences, for example, in employment. If the employment rates of people with and without a disability are compared and a gap is found, that can be taken as evidence of environmental barriers. If people of the same age, gender, area of residence, etc. who have difficulty seeing, for example, have lower employment rates than similar people with no difficulty seeing, then the conclusion is that barriers must exit for people with seeing difficulties.

While the Washington Group Short Set only asks about one aspect of the social model – namely a person's functional limitations, these six questions can be used in conjunction with participation measures (such as employment) to analyze the relationships between individual functioning and participation as affected by the environment. Importantly, the Short Set added to a broader census or survey allows questions on different components of the disability concept to be asked one at a time; it is not good survey practice to ask questions that encompass more than one concept. Better practice is to ask multiple questions about different aspects – individual functioning, participation, environment – and use them together in an analysis to better understand their relation to each other.

IV. The Washington Group Short Set on Functioning (WG-SS)

The first task of the WG was the development of a short set of questions. A short set was needed for inclusion on a census where space is very expensive, where the number of questions must be very limited, and where there is a restriction on the type of question that can be asked. Therefore, the set needed to identify the large majority of people with disability using the fewest questions possible so as to be appropriate for a census. Having a short set also makes it easier for including disability questions on household surveys where, again, statistical offices aim to keep questionnaires as short as possible to increase response rates and data quality while reducing costs.

The WG-SS consists of the following six questions that ask about the degree of difficulty in doing activities in six basic functioning domains.

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)?

Each question has four response categories, which are read after each question.
1. No, no difficulty
2. Yes, some difficulty
3. Yes, a lot of difficulty
4. Cannot do it at all

It is important to ask about the degree of difficulty for two reasons. First, both functioning and disability exist along a continuum, thus it is important to capture a range of difficulties. Second, scaled responses are often more accurate than yes/no responses. Scaled response options provide respondents with varying abilities to self-report their degree of difficulty rather than forcing the respondent into a yes or no category. Scaled response options are also preferred since they avoid a yes response – a choice which is often correlated with other social factors, including stigma.

For many purposes and for international comparisons, a person is considered to have a disability if they answer "a lot of difficulty" or "unable to do" to *at least one* of the six questions. This level of difficulty places the individual at risk of exclusion if there are barriers in the environment. Testing results show that respondents conceptualize "a lot of difficulty" or "unable to do" more consistently across both countries and sub-groups. For this group of people, the risk of non-participation is greater. The conceptualization and the implication of "some difficulties" varies more across countries.

However, people responding "some difficulty" to one or more questions can also be included in the analysis if there are gaps between their outcomes and the outcomes of people answering "no difficulty" to all six questions. This would be evidence that they also face barriers. The appropriate cut-off to choose will be dictated by the outcome of interest and need for the data. A more detailed discussion of this and many other issues can be found on the **Washington Group on Disability Statistics website**.

V.   Limitations in the WG-SS

There are two limitations in the WG-SS, both of which are addressed by other WG tools. The first limitation in the Short Set is that the questions do not apply to children under the age of five, and they miss many children with developmental disabilities over the age of five. For this reason, UNICEF and the WG developed the Child Functioning Module (CFM) which is designed to better identify all children with disability. The CFM has two versions: one for children 2-4 years old and one for children age 5-17 years old. Both are designed for administration to mothers (or primary caregivers). A version of the WG questions for administration to teachers is also currently under development. A lot of information on the design and use of the CFM can be found on the **Washington Group on Disability Statistics website**.

The second limitation in the WG-SS is that it misses many people with psychosocial disabilities. Research from the U.S. shows about half of people with psychosocial disabilities are missed by the six questions in the WG-SS. The half who are identified by the WG-SS are identified primarily because they answered "a lot of difficulty" or "unable to do" to the questions about cognition (remembering and concentrating), communication, and self-care. However, while these respondents are included among the people "with disability", it is not possible – using only the WG-SS – to identify them as specifically having a psychosocial disability. For that reason, the WG developed a set of four additional questions that address anxiety and depression. These additional questions are part of the WG-ES discussed below. They are also included in the Short Set – Enhanced, thus helping to identify people with mental health concerns while still limiting the number of questions that need to be added to a census or survey.

For a discussion of **Other WG-SS Considerations, Questions and Commonly Expressed Concerns**, see **Appendix 1**.

VI. Moving Beyond Disaggregation

The WG has worked in collaboration with the UN International Labor Organization (ILO) to develop a short module to be used on labor force surveys to begin to capture barriers and facilitators in the labor market. As noted earlier in this paper, UNICEF and the WG have developed and are widely using the Child Functioning Module to give greater clarity to statistics on disabled children. The WG, working together with UNICEF, is also testing a module that will generate insights into access to education among children with and without disability.

The disaggregation of SDG outcome indicators, like access to education or employment, will provide evidence regarding the level of participation by people with disability compared to those without disability.

Disaggregation on its own, however, does not address the question "Why?" Why are people with disability not achieving social equality? The answer to that question lies in determining the barriers that are faced by persons with disability in their attempt to achieve equality. For that reason, the WG has developed additional modules to address the most fundamental forms of societal participation for adults (work) and children (school).

VII. How the WG questions Should NOT be Used

Diagnoses

The WG-SS, and even the WG-ES, are in no way detailed enough to diagnose particular medical conditions. The purposes of the WG questions relate to the social model of disability and are not intended to provide diagnosis on the individual level.

Program Eligibility

Often, government ministries are concerned when they see disability prevalence rates of 10 percent or even higher. They think, "How can we possibly provide disability pensions to all of those people? It will bust our budgets." This is because they are confusing the population *identified* by the WG-SS with the population *eligible* for their specific programs, frequently social protection programs. For example, many disability programs are designed to assist people who cannot work because they have characteristics the program defines as a disability. These are typically people with serious impairments, but that group is only a small subset of the people identified by the WG-SS; the WG-SS identifies a population with a much broader range of difficulties. A subset of those identified by the WG-SS would qualify for programs, including social protection programs. Others who might quality for programs based on their functional status would not quality for programs based on other criteria. In addition, some people with severe functional difficulties are employed which may disqualify them for certain social protection programs. So, while many people identified as having a disability by the WG-SS may very well not qualify for disability benefits according to some program requirements, they are still are at risk of exclusion. Only by comparing outcomes for those with functional difficulties to the outcomes of people without functional difficulties can we tell if exclusion is being realized and to what extent (see WG Blog: **Washington Group Questions and the Sustainable Development Goals**).

Identifying people with functional difficulties who are not eligible for a program is important. It can help us see how all people with disabilities are doing, and it can help us evaluate whether a program is well designed and successful.

Service Delivery

The WG questions are not specific or detailed enough to be used to design the delivery of services. A person with trouble walking may need a prosthetic, a wheelchair, a heart transplant, or a combination of these interventions. However, no matter what their clinical situation, the fact that they have difficulty walking does relate to barriers – lack of ramps, elevators, curb-cuts, attitudes, etc. – that put them at risk of non-participation. The WG questions can even be used as a screen for referral to a more detailed assessment that can inform service delivery, but by themselves, they cannot and should not be used for assessment at the individual level.

For a **Brief Introduction to Implementation Issues**, see **Appendix 2**.

VIII. Helpful References and Links

External Links:

1. International Seminar on the Measurement of Disability
   https://unstats.un.org/unsd/disability/Seminar%202001.html
2. United Nations Statistical Commission City Group https://unstats.un.org/unsd/statcom
3. UNICEF https://data.unicef.org/topic/child-disability/module-on-child-functioning/
4. Disability Data Expert Group
   https://www.un.org/disabilities/documents/egm2014/EGM_FINAL_08102014.pdf
5. United Nations Department of Economic and Social Affairs
   https://www.un.org/development/desa/en/
6. 2030 Agenda for Sustainable Development Goals
   https://sustainabledevelopment.un.org/?menu=1300
7. UN Convention the Rights of Persons with Disabilities (UNCRPD)
   https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Internal Links:

1. Washington Group on Disability Statistics website https://www.washingtongroup-disability.com/
2. WG Short Set on Functioning (WG-SS)
   https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/
3. WG Extended Set on Functioning (WG-ES) https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/
4. WG Short Set on Functioning - Enhanced (WG-SS Enhanced) https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-%e2%80%93-enhanced-wg-ss-enhanced/
5. WG/UNICEF Child Functioning Module (CFM) https://www.washingtongroup-disability.com/question-sets/wgunicef-child-functioning-module-cfm/
6. WG/ILO Labor Force Survey Disability Module (LFS-DM): https://www.washingtongroup-disability.com/question-sets/wg-ilo-labor-force-survey-disability-module-lfs-dm/
7. WG Blog Series:
   a. Washington Group Questions and the Sustainable Development Goals https://www.washingtongroup-disability.com/wg-blog/washington-group-questions-and-the-sustainable-development-goals-67/
   b. Are People with Albinism Included in The Washington Group Questions? https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/
8. The Washington Group Short Set on Functioning: Question Specifications https://www.washingtongroup-disability.com/resources/the-washington-group-short-set-on-functioning-question-specifications-205/
9. Translation of the Washington Group Tools https://www.washingtongroup-disability.com/resources/translations-of-wg-question-sets/
10. Cognitive Testing of the Washington Group Translated Questions **https://www.washingtongroup-disability.com/resources/cognitive-testing-of-the-washington-group-translated-questions-210/**

How to contact the Washington Group on Disability Statistics

The WG Secretariat is located at:

The U.S. National Center for Health Statistics (NCHS)
3311 Toledo Road, Room 4114
Hyattsville, Maryland 20782
USA

Email: wg_secretariat@cdc.gov

APPENDIX 1.

Other WG-SS Considerations, Questions and Commonly Expressed Concerns

See the Washington Group website for Frequently Asked Questions (FAQs) and blogs addressing a wide variety of questions people often ask about the WG-SS. Here we include brief responses to a few of the most commonly asked questions.

Does the WG-SS identify everyone with a disability? Does it need to?

The answer to this is easy. No, the WG-SS does not identify all people with disabilities, nor does it need to identify all people with disabilities.

To identify all people with disabilities would require many more than six questions. Space is almost always limited on censuses and surveys, and there are also cost and time constraints. In order to disaggregate for the SDGs, all household surveys or data collections used for SDG monitoring should include the WG-SS. Ideally, the WG-ES should be used, however, the aforementioned constraints may prevent this. Ultimately, which tool to include in a data collection depends upon how much extra value would be added if the Short Set – Enhanced or the WG-ES were used rather than the WG-SS given the additional costs and burden.

Recall the main purpose of the WG-SS is to be able to disaggregate indicators by disability status to see if outcomes for people with disability are different from those without disability – in other words, identifying the disability gap. Ideally, the intent is to identify all persons that meet the definition of having disability. In reality, however, no set of questions on any topic identifies all members of a target population. This is true even for the most widely used and well-known statistics. However, to create accurate and useful statistics, it is not necessary to identify all such people. It is only necessary to identify the large majority and to do so in a way that the results are not biased. If these conditions are met, it is possible to identify associations between disability and various outcomes in the data. Of course, with enough resources more questions can be added. The WG-SS represents the smallest number of questions which can identify a large enough percentage of people with disabilities to make prevalence and disaggregation results meaningful.

Evidence shows when using the WG-SS instead of the SS – Enhanced or the WG-ES, only a small number (a few percentage points) of people with disability are missed. For purely statistical purposes, leaving out this small percentage of people not identified by the WG-SS will have a small impact on measuring the disability gap. While true the small percentage missed also face barriers, there may be no or only negligible underestimation of this gap. Importantly, leaving out this small percentage will not have a significant impact on measuring trends in the disability gap because whatever the initial underestimation would be, it is most likely going to be constant across time, so the changes in the measured disability gap will not be affected. If, for policy purposes, it is important to identify a broader range of people, then more questions are required. This is discussed in the next section.

How do we deal with those who may be missed, such as those with albinism, short stature, and facial disfigurement?

A discussion of who is missed statistically in data collection is different from the concept of 'leave no one behind' referenced in the SDGs and other human rights initiatives. The latter can and must be addressed by politicians, policy makers and advocates. For the purposes of our discussion here on generating statistics for disabled populations, this issue needs to be acknowledged and can be addressed as noted below.

There may be strong policy reasons for wanting to identify the people the WG-SS tends to miss or those who are included but cannot be specifically identified by the questions. For example, the WG-SS captures individuals with psychosocial difficulties through question in the communication, cognition and self-care domains but does not contain questions specifically addressing psychosocial difficulties. However the WG Short Set – Enhanced set (WG-SS Enhanced) does contain questions on anxiety and depression that allow for the identification of persons with difficulties in these domains.

There are also certain impairments not covered by current WG questions. For example, some governments might be particularly concerned about people with albinism, or facial disfigurements, or people of short stature. If that is the case, there is no reason why a set of questions designed to identify these individuals cannot be added to the WG-SS. It is important, though, that those questions follow, rather than precede, the WG-SS, so they don't influence how people respond to the WG-SS (see WG Blog: **Are People with Albinism Included in The Washington Group Questions?**). In other words, the six established questions are asked and then additional questions - that have been tested and validated - can be added after this.

Why is there no reference to long-term vs. short-term difficulties?

One of the most common questions asked about the WG-SS is why no reference is made to whether difficulties are long- versus short-term. Most countries want to identify people with long-term limitations, because they will have a greater effect on participation in society and well-being over time. Often there is an interest because data are being collected to estimate the number of people who would qualify for social protection benefits, eligibility for which is based on having a long-term condition.

On the other hand, if the data are being collected to provide a snapshot of who, at the time of a census or survey, is facing difficulties, and how such a population would benefit from accommodations or universal design, or need assistive devices, medical care, or some other intervention, then identifying people with short-term difficulties is not problematic. For example, if the WG questions were being used as part of an intake procedure at a refugee camp (a use of the WG questions currently being studied) then identifying people with short-term difficulties – like having a broken leg – may be important for determining who should be referred to services.

If those using the WG questions are primarily interested in long-term difficulties, additional questions could be asked of people who identify as having difficulties using the WG questions, such as, "How long do you expect these difficulties to last? Less than 6 months? Between 6 months and a year? Over a year?" Of course, this would add more time to a survey (and would be too much for a census). As noted earlier, such questions would also have to be tested before they were used.

So, should a clause aimed at distinguishing permanent from temporary conditions be included in the WG questions? The WG recommends against this for a number of reasons.

1. *Clauses referring to a length of time or permanent/temporary are complicated and often misinterpreted.* In fact, earlier versions of the WG questions had such clauses and cognitive testing found them to be problematic. Often people ignored the clause altogether, focusing on only a part of the clause, or misinterpreting it. They may think of "permanent" as the fact that they *always* had these difficulties, not that they will always have them moving forward. They, at times, respond to "at least 6 months" as if it were "only 6 months," so temporary conditions were included but long-term ones excluded – the exact opposite of what is intended. Cognitive testing of these questions showed while we may think the question is clear, it often is not. Worse, there is reason to expect less educated people will be more likely to misinterpret the question, so we not only get measurement error but biased measurement error.

2. *People tend to report their usual situation, not a temporary one.* In our cognitive testing we found in most cases people did not report temporary conditions. They understood, for the most part, the questions were aimed at long-term conditions.

3. *Including the small number of people with temporary conditions as disabled does not significantly influence the results on the population level.* The purpose of the WG questions is to obtain disability prevalence and to compare outcomes for people with and without disability. The small number of people with temporary disabilities who identify themselves as having 'a lot of difficulty' or 'unable to do' would add only a tiny fraction to prevalence. The addition is generally not big enough to significantly influence the observed correlation between disability status and employment, education, etc.

So, there is a choice: add a clause to get at the long-term nature of a person's difficulty and introduce measurement error that could be biased, or leave such a clause out and misclassify a small percentage of people as having disability when the limitation is temporary. Based on our testing, we have concluded the second option generates less error and will not affect the types of analyses for which the WG questions are designed.

Can more detail be added?

Disability is an extensive and complicated topic. Six questions only begin to describe it. For that reason, the WG developed the Extended Set. The WG-ES expands the WG-SS both by asking about more functional domains and asking more questions within each domain. The WG-ES is too long for a census and may be too long to include as part of the core questionnaires used for generating SDG indicators. However, it can be used as a special module for a more detailed analysis of disability. It has been used, as such, in several national disability surveys and health surveys and is also being used by sub-national groups, researchers and non-governmental agencies for such purposes.

The following functional domains in black are included in the WG-SS. Questions in red are added to comprise the SS – Enhanced, and those in blue are the additional questions that make up the WG-ES. It should be noted that people with significant upper body functional limitations will most likely report they have difficulties with self-care in the WG-SS.

- vision
- hearing
- mobility
- cognition
- self-care
- communication
- affect (anxiety & depression)
- upper body functioning
- pain
- fatigue

The WG-ES also includes additional questions in domains covered by the WG-SS including functioning with and without the use of devices/aids where applicable.

For more information on the Washington Group on Disability Statistics, visit: http://www.washingtongroup-disability.com/.

APPENDIX 2.

Brief Introduction to Implementation Issues

Modifications to the WG Questions: Some Frequently Asked Questions and a few 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 National Statistics Offices (NSOs) begin incorporating the questions into ongoing censuses or surveys including translation, use of a screener, and the categorical response options. Modifications to the original set of six questions, whether minor or 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 extensive testing that has been done by the Washington Group and by partners over the past two decades in countries in every region, including low-, middle-, and high-income countries. Those wishing to make modifications not mentioned below should **contact the Washington Group Secretariat (see page 9)** for assistance.

What is the purpose of the introductory statement?

An introductory statement (e.g., 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 a number of different topics with topics changing quickly. The purpose of an introductory statement is to inform the respondent the next set of questions addresses a new topic and has a health context. For example, if the WG questions followed a series of questions on sanitation, the introductory statement provides a transition to the health domain. In a survey where this module might follow other health-related questions and where the context is already established, the introductory statement can be dropped if the flow of the questionnaire has already established that questions are being asked in the 'health' domain.

Definite Don't: DO NOT use the word "disability" in either the questionnaire or 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 asking people to respond to questions they may feel are invasive or link to cultural stigmas or taboos and to reduce response variability due to differential understanding of the term, more neutral language must be used. For this reason, as well, rather than ask directly about and using the term 'disability', 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 they are recognized by people no matter what language is used to ask the questions.

On the other hand, use of the term disability in the questionnaires or in interaction between the interviewer/enumerator and the respondent appears to reintroduce variability in how the term is understood and can introduce stigma and reduce or eliminate the validity of the questions set.

Definite Don't: Do not use a screener

Evidence shows 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 force a respondent to make the choice of affirming disability which in some cultures is associated with stigma and discrimination.

Some screeners do not use the term disability but ask about specific medical diagnoses. 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. Moreover, having a condition does not translate into having a functional limitation associated with that condition. For example, arthritis is associated with difficulty walking but two individuals diagnosed with arthritis don't necessarily have the same functional level. One might have a great deal of difficulty walking while the other has very little difficulty. Knowing someone has a condition does not tell you the extent of their functional limitation if any.

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.

Can I change the wording in the questions?

It is not recommended to change the wording in the six questions. The only exception to this is that, 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, glasses are far more widely used. To indiscriminately omit the clause "…even if wearing glasses" would grossly inflate disability prevalence since many people who use glasses or lenses to correct a visual impairment would answer affirmatively (many would report serious difficulties in seeing without their glasses) given that glasses often completely correct vision (see **The Washington Group Short Set on Functioning: Question Specifications**). 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?
Yes
No
If Yes: Do you have difficulty seeing even if wearing your glasses?

If No: Do you have difficulty seeing?

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 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 only as having the difficulty or not. It is better to offer a range of responses as in the WG questions. The four 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:

no difficulty   **some**   **a lot**   **cannot do at all**
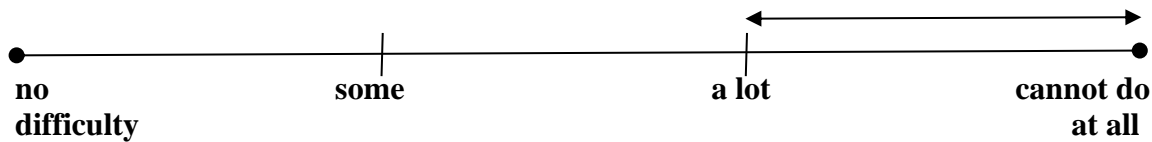
The distribution above creates four points equally distributed among the continuum allowing respondents to easily discriminate among the options. The recommended cut-off (at *a lot of difficulty*) identifies those with the intended level of difficulties.

How important is translation of the questions into local languages?

The WG has a strong commitment to the accurate translation and dissemination of all Tools into a range of languages, including all the official UN languages and a range of national, regional and local languages.

The need for accurate translation will serve both national and international purposes. Few countries have only one language in common daily use. Researchers, demographers, and survey methodologists are often confronted with the challenge of translating survey questions into multiple languages and often adapting to multiple dialects. This is not unique to disability questions; the need to appropriately translate questions is a requirement for all questions that will be used across populations speaking different languages or dialects.

A good translation goes beyond the literal translation of *words* but ensures that *concepts* are appropriately reflected and consistent in all versions of the questionnaire.

As an example, the WG Short Set question that concerns cognitive difficulty is: "Do you have difficulty remembering or concentrating?" In a few instances it has been observed that 'difficulty remembering' has been translated as 'difficulty memorizing' or 'difficulty with bad memories'. These three constructs are not the same; the first focuses on cognitive abilities (this is what we are interested in), the second introduces learning abilities, and the last one can be about affect rather than cognition. For consistency, it is *essential* the translation from source to target language captures the *same construct*.

Questions should be properly translated and translated versions of the questions should be cognitively tested. For more information on translation of the questions, see: **Translation of the Washington Group Tools**, and for the testing of translated versions of the questions, see: **Cognitive Testing of the Washington Group Translated Questions**. The Washington Group recently updated the questionnaires on its website – including the WG Short and Extended Set of Questions – in a number of different languages. We are adding more languages all the time, and readers who do not find the languages they need on the website are encouraged to contact the WG Secretariat (see page 9) – to see if a translation of the language they are working with is in process. (The WG would also welcome agencies and researchers who have made translations of the Tools into languages not currently available on our website, to share these translations with us). It is not possible for the WG to test the translated questionnaires received from countries. Cognitively testing translations is recommended even for those translations that have been done professionally.

How should the questions be administered?

It is recommended 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, no difficulty
Yes, some difficulty
Yes, a lot of difficulty
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 question. They should be repeated as soon as the respondent does not use the required category (e.g., responds 'yes') or after the second or third question. Enumerators will require training in when it is appropriate to not read the answer categories.