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The Data Collection Tools Developed by the Washington Group on Disability Statistics and their Recommended Use

Introduction

The Washington Group on Disability Statistics (WG), a city group established under the United Nations Statistical Commission, was formed to address the urgent need for population-based measures of disability by promoting and coordinating international co-operation in the area of health statistics focusing on disability data collection tools suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability that is comparable throughout the world. The WG has developed data collection tools for use in national censuses and surveys that produce internationally comparable data on disability.

Disability is a complex and dynamic process that presents considerable challenges for data collection. The definition of disability has changed over time and is currently conceptualized as the outcome of the interaction between a person with a functional limitation (difficulties doing basic functional activities) and an unaccommodating environment resulting in the inability to fully participate in society. Thus, to provide complete information on all aspects of disability would require extensive and detailed data collection on almost all aspects of life including body structure and function, individual functional abilities across the full range of activities, a full description of all aspects (physical, cultural, legal) of the environment in which a person lives, and levels of participation across the full range of social roles (e.g. work, school, social interaction, community engagement, civil participation). This is not practical and for many purposes is not necessary. Multiple tools can be used to address the different components of the disability framework.

This first in a series of **Washington Group Implementation Documents** covers the tools developed by the Washington Group to collect internationally comparable disability data on censuses and surveys. The WG-SS, WG-ES and CFM are included, as well as tools now in development. Use of the WG-SS for the purposes of disaggregation is also discussed.

Additional Implementation Documents cover: The Washington Group Short Set on Functioning; Translation of the Washington Group Tools; Question Specifications; Analytic Guidelines; and other tools developed by the WG and partners for the measurement of disability.

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

The data collection tools developed by the WG are easily incorporated into ongoing national data collection systems, as well as topic-specific surveys, programmatic, and research data collections. The tools are designed to complement each other, making it possible to use information from different sources together. When selecting a tool, it is critical to match the tool with the intended use of the data and the data collection method.

This overview describes the WG data collection tools - both those currently available and those under development – and how they relate to each other so that users can select the most appropriate tool for their needs. All tools have undergone extensive testing and the results of the tests are available on the WG website. The website also contains more detailed information on each tool and on the work of the WG.

THE WG SHORT SET ON FUNCTIONING

The first tool developed by the WG is the Short Set on Functioning (WG-SS). The tool, a set of six questions, was developed in response to the stated need of member countries for a short module that can be added to decennial censuses, which in many countries can be the sole or most reliable means of collecting population-based data. Because of the restrictions inherent in the census format, the module had to be short and parsimonious. While developed initially for censuses, the brevity of the module is also well suited for inclusion in surveys for the purpose of disaggregating outcome indicators by disability status.

The 3rd Revision of Principles and Recommendations for Population and Housing Censuses (United Nations Statistical Division, https://unstats.un.org/unsd/demographic/sources/census/census3.htm) contains recommendations pertaining specifically to the collection of disability data on censuses. Disability is categorized as a ‘core topic’ indicating that the majority of the regional recommendations in previous census decades have designated disability as a priority topic. Furthermore, suggested tabulations based on the recommendations for disability data collection using the WG-SS are provided. Similar recommendations for the 2020 Censuses of Population and Housing have been prepared by the Conference of European Statisticians in cooperation with the Statistical Office of the European Union.

To maximize international comparability, the WG-SS obtains information on difficulties a person may have in undertaking basic activities that apply to people in all cultures and societies and of all nationalities and so are universally applicable. Difficulties in these basic activities in a non-accommodating environment are associated with a higher risk of participation restrictions. When analyzed in conjunction with other information collected on censuses and surveys, it is possible to compare whether difficulties in basic activities are associated with participation restrictions or if the necessary accommodations have been made so that all persons can fully participate in society. This definition is in keeping with the United Nations Convention on the Rights of Persons with Disability (UNCRPD) and its goal of full and effective participation and inclusion in society (Article 3, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-3-general-principles.html).

Given the need to keep the module short, a single question per functional domain is included. The final set of questions includes difficulties seeing, hearing, walking or climbing stairs, remembering or concentrating, self-care, and communication (expressive and receptive). Other functional domains were considered, but not included as some would require more than one question per domain and some domains, such as affect or pain, are not appropriate for a census. It is acknowledged, therefore, that the short set of six questions will not identify all persons with all types of difficulties in basic activities. However, evidence shows that using these questions covering major functional domains identifies the large majority of people with disabilities, and so is useful for making inferences about the characteristics of people with disabilities in the population and their outcomes that are critical for policy planning and evaluation. To identify those remaining, a more extensive set of questions is needed, for example the WG Extended Set on Functioning summarized below.

The WG-SS was not designed for use among children, and does not include key aspects of child development important for identifying disability in children. The Module on Child Functioning (described below) was designed specifically to meet the needs of identifying and measuring disability in children.

THE WG EXTENDED SET ON FUNCTIONING

Upon completion and adoption of the WG-SS, the WG embarked upon the development of an Extended Set on Functioning (WG-ES) that would allow for the collection of additional data on domains of functioning not included in the WG-SS; for example, affect (anxiety and depression), upper body functioning, and pain and fatigue. These were not included initially because a single question could not be crafted that captured the essence of functional difficulty in these domains. The WG-ES also collects more information for certain domains included in the WG-SS. This additional information allows for greater granularity along the continuum of functioning. For example, more detail on functional ability is obtained for hearing and mobility.

The WG-ES also begins to explore the connection between functioning and the environment through the inclusion of questions on the use of assistive devices and personal assistance in the mobility (walking) domain.

The WG-ES includes about 35 questions and is intended for population-based household surveys (demographic and health surveys-DHS, household income and expenditure surveys-HIES etc.) or as part of a larger disability survey. The questions are designed for the adult population 18 years and above.

It is important to note that the six Short Set on Functioning questions are embedded into the Extended Set on Functioning.

THE WG/UNICEF CHILD FUNCTIONING MODULE

As noted above the WG acknowledged early in its work that the WG-SS questions was not ideal for the child/adolescent population. To address the unique situation of children, the WG therefore embarked upon the development of a separate module that would specifically address child functioning. This work began in 2009 and United Nations Children’s Fund (UNICEF) joined the collaboration in 2011.

The Child Functioning Module (CFM) follows the same principles as the earlier WG modules: to determine disability through a series of questions on difficulty in functional domains that would place a child at risk of participation restrictions in a non-accommodating environment. The CFM is comprised of two sub-modules: one for children 2-4 years of age and another for children 5-17 years of age. Domains of functioning for children 2-4 years of age include: seeing, hearing, mobility, fine motor, communication, cognition (learning), playing and controlling behavior. Domains of functioning for children 5-17 years of age include: seeing, hearing, mobility, self-care, communication, cognition (learning, remembering and concentrating), accepting change, controlling behavior, relationships and affect (anxiety and depression). The sensory questions allow for an introductory question on the use of glasses or hearing aids as is done for the WG-ES for adults.

Six of the domains mirror those included in the WG Short and Extended sets of questions, but the questions used in the child module are modified slightly to be suitable for use with this subpopulation.

The CFM is intended to be administered to the child's mother. In cases where the mother is not alive or not living in the same household, the primary caregiver is the recommended respondent for this module.

MODULES UNDER DEVELOPMENT

The WG is working with partners to develop two additional modules that focus on participation and the barriers and facilitators that affect level of participation. The WG and UNICEF are developing an inclusive education module that would be used in conjunction with the CFM. This module focuses on measuring barriers & facilitators to education for children with and without disabilities. Data are collected under three main domains related to the environment and within the context of school participation: attitudes, school environment (including getting to school, accessibility and affordability), and a set of questions designed for children currently out of school.

The WG is working with the International Labour Organization (ILO) to develop a module on employment. Questions for selected domains from the WG-ES are used in conjunction with the WG-SS and information on work related barriers and facilitators to address issues related to full participation in work.

SELECTION OF THE APPROPRIATE DATA COLLECTION TOOL

A data collection tool should be selected to meet the objectives of the data collection and the data collection platform to be used.

The **Short Set on Functioning** is recommended for data collections in

(1) Censuses where space is very limited.
(2) Targeted surveys where at least some information is obtained on all or multiple members of the household/family.
(3) Broad based household surveys that cover a wide range of topics where information is obtained on all household/family members (e.g., living standard measurement surveys or household income and expenditure surveys)

The WG-SS tool is, as the title states, short (only six questions) and it is easy to administer. While self-response is preferred, the WG-SS can be administered to a household or family respondent following the usual practice of the data collection. When included in such surveys, the WG-SS should be used to disaggregate the information obtained on the survey's main focus by disability status in order to compare the outcomes for persons with and without disability. The WG-SS implementation guide provides detailed information on how to construct the disability indicator.

The WG-SS is not recommended for reporting on disability in children, as information will be missed on key aspects of child development, including learning, interacting with peers, coping with change, and focusing attention.

In cases where the Child Functioning Module cannot be incorporated into ongoing data collections due to design requirements, such as in censuses which focus on the total population, but where the WG-SS is included, the WG-SS questions should only be administered for the population five years and older.

The WG-SS should not be used to collect data on children below the age of five. When the WG-SS is used for children aged five and older, it is important to emphasize that estimates of prevalence would be underestimated. Under these circumstances, the fact that estimates for children only apply to a subset of key functional domains for this age group would need to be clearly documented when reporting results. In addition, the wording of some of the WG-SS questions, such as on self-care, are not optimized for children. The questions in the CFM were intentionally modified in the domains covered by both question sets to address this limitation. Finally, the mother (or primary caregiver) is the best informant when obtaining information on children. For many surveys that will include the WG-SS, the mother is unlikely to be the survey respondent.

Taking into consideration the limitations outlined above, any analysis of the information obtained using the WG-SS specifically for children, including disaggregation, should refer to children having difficulties in only those six domains covered by the WG-SS. A more accurate definition of disability among children would require the full range of functional domains included in the CFM. This module should be used in data collections where children are a major focus or where key findings will be reported separately for children.

The **Extended Set on Functioning** is recommended for use in surveys in order to obtain information on domains covered by the WG-SS as well as those not covered. The WG-ES should be used in health surveys and surveys that focus specifically on disability but also should be included in surveys that focus on other topics where the survey design is such that:

a) Extensive information is collected on selected adult family members.
b) Information is collected from the respondent, and not a proxy, unless the respondent is unable to participate due to a health problem or functional limitation.

This module should not be used for children. Instead, the CFM should be used.

Including the WG-SS each year on ongoing surveys, and the WG-ES on a periodic basis, is one way to reduce burden but assure that information on all functional domains will be available.

When the WG-ES is used, estimates of disability prevalence will increase. This is because additional domains are included, as well as additional questions within the WG-SS domains. However, as the WG-SS is embedded in the WG-ES, it is possible to identify the additional people with disabilities identified by the WG-ES, and to make comparisons with results of other data sets that use only the WG-SS.

Depending on the focus of the survey, only selected domains from the WG-ES can be included however, the inclusion of all domains will provide a fuller description of functioning. The WG-ES implementation guide provides detailed information on how to construct the disability indicator.

As in all data collection, the choice of respondent will impact the results. For disability among adults, a self-respondent is preferred. This may not always be possible, such as in cases when the WG-SS or WG-ES is added to existing surveys where the existing protocol for administering the survey is pre-determined and may not consist of self-response. Therefore, in any analysis the type of respondent should be noted.

The **Child Functioning Module** is recommended for use in surveys that either focus on children, or that contain modules that focus on one or all children in the household. The child functioning module should always be used in surveys that focus on education. The domains included in this module address the unique situation of children and are critical for understanding participation in educational activities which is children’s primary activity and which will have major impacts on their lives as adults. Information obtained using only the WG-SS will not provide information on these key domains.

The WG tools were developed as interrelated components that would describe functioning in different population subgroups depending on the objectives and selected platform for data collection. The analysis guides for the three survey components will provide information on how to relate the information produced using the different tools on the same study population. The data collection tools were developed to meet user needs and reflect the need to balance requirements for a very short set of questions for some purposes against the need for more detail for other purposes and for specific age groups.

DISAGGREGATION BY DISABILITY STATUS

Disability is not inherently a dichotomous concept; it exists on a continuum. How that continuum is created and which cut point is chosen to define the population with disabilities will have a direct effect on the prevalence of disability and the characteristics of the population with disabilities. Which questions to include and where to define disability is a function of the data collection objective. When reporting information on disability, it is essential to also report on the questions used to define disability.

There are two necessary conditions that must be met in order to disaggregate data by disability. First, the indicator must already be collected and second, there must be a straightforward and simple way to identify persons with disabilities so that the indicator can be disaggregated by disability status.

The current Sustainable Development Goals (SDGs) framework addresses the first condition, as the agreed set of indicators will be used for monitoring and evaluating progress in the implementation of the SDG goals and targets. The second condition has also been met with the development of census and survey tools adopted by the WG and partners. WG tools can identify persons with disabilities for disaggregation purposes in an internationally comparable way.

Overall, there is broad international consensus that the WG-SS represents the international best practice for disaggregating data by disability. United Nations Statistical Division (UNSD) and the UN Economic Commission for Europe have recommended the WG Short Set on Functioning for use in the current round of population censuses (see: https://unstats.un.org/unsd/statcom/doc15/BG-Censuses.pdf). A UN-sponsored Disability Data Expert Group has recommended them for use in disaggregating the SDGs and for monitoring the implementation of the UNUNCRPD. A Joint Statement provided by the Disability Sector (composed of UN Member States, UN Agencies, organizations of persons with disabilities, civil society and independent experts) to the Interagency Expert Group on SDGs (IAEG-SDGs) has recommended the

WG Short Set on Functioning for the purposes of SDG data disaggregation for adults and the UNICEF/Washington Group CFM for disaggregation by disability among children in order to ensure international comparability and comparability over time (see: http://www.internationaldisabilityalliance.org/data-joint-statement-march2017). Countries in the Asia and Pacific Region, through the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), have recommended their use in producing the Incheon "Making the Right Real" Disability Strategy indicators. Bilateral agencies have also adopted tools developed by the WG. For example, both DFID (UK Department for International Development) and DFAT (Australian Department of Foreign Affairs and Trade) have determined that the questions be used for monitoring the effectiveness of their programs in reaching persons with disabilities.

How to use the Short Set on Functioning to Disaggregate Data by Disability Status

Collecting data using the WG-SS provides valuable insight into whether those identified with disabilities are benefitting from policies and programs designed to improve participation. The disaggregated data can be used to evaluate these programs and policies and determine whether the needs of all population sub-groups are being met. The questions can be asked at several points in time to see if progress has been made during an intervention period and to ascertain if people with disabilities are being included or left behind. The questions can be added to existing or planned large- or small-scale surveys or can be included into a program's usual management/monitoring and data collection processes. For example, the questions could be used in an existing employment survey to disaggregate access to employment by disability status or can be asked as part of an intake form for those seeking general, non-disability specific services to see if the service is being accessed by persons with disability to the same extent as it is accessed by persons without disability. As a group, the WG-SS questions can be administered in just over one minute, which does not impose a significant administration burden on existing instruments.

Following standard best practices, any reporting of data collected using the WG-SS needs to articulate clearly how the questions were used, the age range of participants, and the cut-off point used to determine disability status.

For example, the table below shows employment status disaggregated by disability status using data from a national survey. Disability status is determined using the WG-SS. Four possible cut-offs are presented: the recommended cut-off, at least one domain with reported difficulty of a lot or cannot do, is highlighted in red. At the recommended cut-off, the estimates for those 18-64 years of age illustrate that those with a disability are much less likely to be working (30.8%) then are those without a disability (73.5%).

The table also clearly illustrates how different cut-offs elicit different results: higher prevalence and less disparity in employment when the cut-off includes those with minor difficulties; and lower prevalence and greatest disparity when the cut-off is more restrictive and includes only those with the most severe difficulties. If this survey was repeated in five years, it would be possible to determine if programs that were put in place to increase employment among those with a disability were having the desired effect by showing whether the employment rates for those with a disability were approaching the rates of those without.

Employment[1] disaggregated by disability status[2]: adults 18-64 years

		% working	
Person with disability has at least:	Overall prevalence	Without disability	With disability
1 Domain ‘some difficulty’	35.4	76.6	60.2
2 Domains ‘some difficulty’	14.9	74.6	48.5
1 Domain ‘a lot of difficulty’	6.6	73.5	30.8
1 Domain ‘unable to do it’	1.2	71.4	14.6

Data Source: U.S. National Health Interview Survey, 2013.

[1] NHIS question: What was your employment status last week?

[2] Disability status determined by use of the Washington Group short set of questions. The sub-population *with disability* includes everyone with at least one domain that is coded as *a lot of difficulty* or *cannot do it at all*.

Why is this important?

Understanding the exact nature of the barriers faced by persons with disabilities and determining the actions necessary to equalize participation requires the collection of extensive and detailed information. Disaggregating outcome indicators, such as the SDGs, or programmatic objectives, to determine if gaps exist between those with and without a disability is a necessary first step towards addressing disparities. Doing so only requires the addition of a small set of questions on already existing data instruments. The importance of disaggregation is illustrated by an example in the area of education. In recent years, the rate of primary education has increased significantly, in no small part from efforts to build more schools and train more teachers. A logical conclusion would be that to address those last few percent of children not in school, a country should simply build even more schools and train more teachers according to past models. But if the remaining out-of-school children are out of school for reasons associated with other characteristics – such as disability – then only doing what has been done in the past may not get a country that much closer to universal primary education. It may require different actions, like making schools, school materials and curricula more accessible. If school enrolment was not disaggregated by disability status, we would not know that children with disability were not attending school at the same rate as those without disability – and interventions would not be initiated to address this disparity.

For more information, please refer to the Washington Group website:
http://www.washingtongroup-disability.com/

For content of Washington Group tools, please refer to:
http://www.washingtongroup-disability.com/washington-group-question-sets/