

**Development of an Internationally Comparable Disability Measure for Censuses:  
Challenges and Opportunities**

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## **Introduction**

Over the past few decades issues of disability definition and measurement have been the focus of international interest and debate. Of particular relevance to this paper are the shift in focus from the medical to the biological/psychological/social model [1- 5], the application and operationalization of the International Classification of Functioning, Disability and Health (ICF) [5-8], the debate on the suitability of disability-adjusted life years (DALYs) for measuring or summarizing disability [9-12] and the call for improved and more comparable statistics on disability. Most recently, the need for comparable disability data internationally has been championed in the WHO/World Bank World Report on Disability [13]. It is from these debates and discussions that the Washington Group on Disability Statistics (WG) has been able to develop and promote a methodology for the measurement of disability that would produce comparable data cross-nationally.

Governments rely on high quality statistics to develop and evaluate policies and programs with the objective of improving the lives of the people they serve. While most of the information is used for domestic purposes, there is a long standing interest in making comparisons with other countries not only to see how one's own country ranks against others, but to benefit from other's experiences. In order for these comparisons to be meaningful, the information itself must be comparable across countries; the indicators used must address the same constructs and the data collection process must not introduce differences that would affect the relevance and validity of the comparisons. Many countries collect information on disability but disability statistics have long been among the best examples of indicators where international comparisons are difficult. The fact that there are differences among countries does not mean that the data are not

comparable but when the differences exhibit unexpected patterns, questions are raised. This has been the situation with disability statistics. Observed differences whereby the most developed countries show the highest disability rates and the least developed countries the lowest are counterintuitive. A closer examination of how the data have been collected illustrates that there are major differences in approach, definition and methods [13, 14]. This lack of comparability has hampered not only international uses of the data but also draws into question the usefulness of the information for domestic purposes.

Only a brief overview of the activities of the WG can be presented here. For more detailed information, readers are encouraged to access the references and links mentioned in the article.

### **The Washington Group on Disability Statistics**

One of the major conclusions of the June 2001 United Nations International Seminar on the Measurement of Disability was the need for comparable population-based measures of disability for domestic use and for international comparisons. The Washington Group on Disability Statistics (WG) was constituted by the UN Statistical Commission to meet this need.

The WG aims to promote and coordinate international cooperation in the area of health statistics with a primary focus on disability measures. The group's first task was to develop a short set of disability measures suitable for use in censuses, sample-based national surveys, or other statistical formats that would produce comparable data [15]. When this was accomplished, the group went on to develop extended sets of survey items that would address the broadest set of concepts associated with disability. The WG has membership from a wide range of countries (82 have attended at least one annual WG meeting) characterized by different geography, language

and level of development. Through 2011, the WG has met eleven times (Washington DC (2002); Ottawa (2003); Brussels (2004); Bangkok (2004); Rio de Janeiro (2005); Kampala (2006); Dublin (2007), Manila (2008); Dar es Salaam (2009); Luxembourg (2010); and Southampton, Bermuda (2011)). The WG has also fostered international cooperation by working with the UN and other international organizations. (Details of the WG organization, history and accomplishments are available online at: [http://www.cdc.gov/nchs/washington\\_group.htm](http://www.cdc.gov/nchs/washington_group.htm).)

### **Measuring Disability**

Defying a singular definition, disability is a complex concept involving the interaction of a person's ability to function and his/her environment (physical, social, cultural or legislative) with the focus often being on the negative impact of environmental factors on one's ability to participate. Disability data are collected for different purposes and each purpose requires a different data collection approach. Measurement strategies need to take these complexities into account if the resulting data are to be comparable. The WG utilized several mechanisms to optimize data usefulness and comparability.

The first step was to identify, among the many purposes for which data would be needed, a specific purpose for the disability measure. The WG chose to develop questions to address the issue of whether persons with disability participate in society (such as in work, school and community life) to the same extent as persons without disabilities [15]. This objective was considered that which best addressed the broadest policy issues, while capturing personal functioning rather than medical diagnoses. It is also consistent with the policy perspective illustrated in the UN Convention on the Rights of Persons with Disabilities [16]. There was also

agreement that it would be possible to create questions to meet this objective that would produce internationally comparable data. The intent was to construct questions that would obtain information on functional difficulties across domains most closely associated with activity and participation restrictions. To enhance comparability and utility, the following criteria were used to select domains: simplicity, brevity, universality and comparability. The WG used the International Classification of Functioning, Disability and Health (ICF) [4] as the conceptual framework for the questions, focusing on activity limitations and later, through data analysis, participation restrictions. Since the ICF does not provide operational definitions or a way to measure the concepts, the next step was to translate concepts into questions.

### **The WG Questions Sets**

The short set of questions for use in censuses and surveys was developed in accordance with the Fundamental Principles of Official Statistics [17, 18]. The questions cover difficulties someone may have in basic activities and body functions associated with maintaining independence: seeing, hearing, walking, cognition, communication, and self-care; and are presented below:

1. Do you have difficulty seeing, even if wearing glasses?<sup>1</sup>
2. Do you have difficulty hearing, even if using a hearing aid?<sup>1</sup>
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 (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

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<sup>1</sup> 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.

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 WG recommends [19] that the following cutoff be used to define the populations with and without disabilities for the purpose of computing disability prevalence rates and reporting to the UNSD for international comparisons:

The sub-population *disabled* includes everyone with at least **one** domain that is coded as *a lot of difficulty* or *cannot do it at all*.

This recommendation is not meant as a restriction and the WG encourages countries to report disability based on other response cut-offs that would describe milder levels of functional difficulty and allow for the analysis of the continuity of disability in a population based on different levels of severity.

The WG acknowledges that, while the short question set does not capture all people at risk of experiencing restricted activity and participation, the information that results from the use of these questions will, a) represent the majority of, but not all, persons with limitation in basic activities, b) represent the most commonly occurring limitations in basic activities, and c) be able to capture persons with similar problems across countries. To fill that gap, ‘extended question sets’ would be developed to capture more information in the six short set domains (e.g., functioning with and without assistance or assistive technologies, age at onset and impact of the difficulty on peoples’ lives), as well as to add more domains such as learning, affect, pain and fatigue. The extended set of questions on functioning are intended for use as components of population surveys, as supplements to surveys, or as the core of a disability survey.

In developing survey questions to measure functioning and health state, a notable challenge is to account for the numerous ways that respondents across differing cultures, languages and socio-

economic conditions might interpret and process questions especially given that disability is a particularly complex concept, involving varied meanings, attitudes and types of experiences. Because social context and cultural circumstances inform the way respondents interpret, consider and ultimately respond to questions, these differences can lead to systematic measurement error in survey data. Consequently, there is a real risk that these response process biases are wrongfully construed as real differences in the phenomena of study.

In order to measure potential response process biases, questions were evaluated using cognitive testing methods. Cognitive testing explores how the respondents understood what the questions were asking, whether this understanding was consistent across respondents; whether this understanding was consistent with the developers' intent; whether the questions meant the same in all the languages and in all cultures; and whether respondents recall information and construct an answer using similar processes [20].

In developing the short and extended sets of disability questions on functioning, the WG has conducted three large scale evaluation studies. The first cognitive interviewing study of the short set of questions involved 1290 respondents in fifteen countries (Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda and Vietnam) [20]. Examining response patterns (consistencies and inconsistencies) across various questions allowed for an evaluation of the WG questions in the absence of a gold standard. The results both supported the reliability of the WG short set of questions and demonstrated the usefulness of this approach for testing the design of cross-national indicators. Another round of testing involved 100 semi-structured, qualitative cognitive interviews of the

extended set of questions on functioning conducted in seven countries (Spain, Italy, Portugal, Germany, Switzerland, France and the United States). The specific objectives of this study were to identify the: 1) respondents' understandings of what specific questions were asking, 2) processes used by respondents to formulate their answers to the questions, and 3) types of response error encountered. The third evaluation utilized a mixed method design. First, 143 total semi-structured, qualitative cognitive interviews were conducted in 6 countries (Cambodia, Kazakhstan, Maldives, Mongolia, Philippines, Sri Lanka) and based on the analysis of those interviews, follow-up probe questions were developed for use in field studies. The survey questions and the probes were administered in field tests of 1000 standardized face-to-face survey interviews on random samples in each country. The information from the follow-up probe questions was used to examine the extent to which the survey questions were eliciting comparable and valid information. The probe questions were also used to identify ways to categorize the population according to levels of disability. Overall, the mixed-method approach was a powerful technique that provided valuable insight into question performance. Results of the mixed-method testing of the extended set of questions are available at:

<http://www.unescap.org/stat/disability/analysis/>.

## **Discussion and Conclusions**

Working collaboratively with many countries from all regions of the world, the WG was able to develop and test questions for use in censuses and surveys to produce internationally comparable data. The short set provides a comparable mechanism for identifying a population at risk for restrictions in the ability to fully participate in society due to functional limitations in key domains and this approach has been incorporated into the UN Principles and Recommendations

for Population and Housing Censuses [21]. A major challenge faced by the WG in developing the short set of questions was to attempt to capture the complexity of disability in a parsimonious manner. The WG has acknowledged that the six questions do not cover all functional domains equally well. Specific questions on upper body functioning, difficulties that relate to intellectual or developmental disability (other than those related to remembering and concentrating) and emotional or psychological difficulties are either absent or limited in scope. The WG short set was designed to be used in national censuses and this objective limited the number and format of the questions. The functional domains represented in the short question set, selected using the criteria of simplicity, brevity, universality and comparability, are those that have most often been found to limit an individual and result in participation restrictions [15, 22]. The WG expects that the information that results from the use of these questions will, a) represent the majority of, but not all, persons with limitation in basic activities, b) represent the most commonly occurring limitations in basic actions, and c) be able to capture persons with similar problems across countries [18]. Currently approximately 25 countries have indicated that they intend to use the WG short set of questions on this current round of censuses. The WG short set of questions has also recently been added to the National Health Interview Survey (NHIS) in the United States. Data analyses pairing the WG short set with other more detailed measures of functioning and health on the NHIS are currently on-going.

In the meantime, the WG has gone on to fill some of the gaps not covered by the short set through the development of extended sets of questions. The extended set of questions on functioning describes a broader picture of disability in a population beyond the six functional domains of the short set. The WG is also currently working on an extended set of functioning

questions specifically targeted to children and youth, and considering the development of questions on environmental barriers to participation.

Many of the steps taken by the WG in the development of questions on disability have been acknowledged in the World Report on Disability [13:45-47] which recommended the adoption of the ICF, the call for improved national disability statistics and improved comparability of data, as well as the development of appropriate tools (both quantitative and qualitative methodologies) to improve and expand data collection on disability. According to the World Report on Disability, in order to improve national disability statistics it is important that the routine collection of disability data become incorporated into national disability programs. The Report notes that the short set of questions developed by the WG provides a core set that can be expanded to meet country needs.

Finally, by fulfilling the specific purpose for which the WG disability measure was developed, the equalization of opportunity and the extent to which persons with disability participate fully in society, the WG short set questions will contribute to monitoring if, over time, the objectives of the UN Convention on the Rights of Persons with Disabilities have been achieved [23].

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