

Disability Information from Censuses

Washington Group on Disability Statistics (WG)

New Question Set on Disability Developed for Use on Censuses

A new set of questions on disability for use on national Censuses has been developed, tested and adopted by the Washington Group on Disability Statistics (WG), a United Nations (UN) sponsored City Group commissioned to improve the quality and international comparability of disability measures. The approach taken by the WG represents a break with methods used in the past. 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. The focus is on functioning in basic actions in contrast to approaches that are based on a medical model which focus on impairments or bodily functions. The UN Principles and Recommendations for Population and Housing Censuses incorporates the approach taken by WG. (See: Section VI-8: Disability Characteristics pages 178-183, and Tabulations on Disability Characteristics pages 292-294; available online at: http://unstats.un.org/unsd/demographic/sources/census/docs/P&R_Rev2.pdf). A more detailed discussion of the development of the WG question set, including the conceptual framework and data collection objectives, can be found in the Washington Group Position Paper: Proposed Purpose of an Internationally Comparable General Disability Measure (WG3.6), available online at: http://www.cdc.gov/nchs/washington_group/wg_meeting3.htm#papers.

The question set was designed to identify the subpopulation that is at a greater risk than the general population of experiencing restrictions in social participation, for example in employment, education or civic life. Risk is increased as a result of difficulties experienced in basic functional domains or actions such as seeing, hearing, walking, cognition, self care and communication. The 'at risk' population captured by the short set of questions will include persons with difficulties or limitations in basic actions who may or may not also experience restrictions in participation. Actual participation levels will depend on the availability of assistive devices, a supportive environment and other resources and these will vary within the group identified as being at increased risk (i.e., disabled). Using these questions in conjunction with other questions on a Census, it is possible to compare the actual level of participation of the subpopulation at higher risk with those not experiencing similar functional difficulties. Observed differences in levels or degree of participation reflect the need for societal accommodation to equalize opportunities for full societal inclusion. This approach to disability is a central tenet of the UN Convention on the Rights of Persons with Disabilities.

Given the limitations of the Census format, it is not possible to include all aspects of functioning or all basic actions in the question set. However, the selected domains encompass core aspects of functioning and will identify a large proportion of the population at risk of experiencing restrictions or disadvantages in the major life areas of education, employment, and family, social and civic life.

The final short question set is:

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 (customary) 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 severity scale is used in the response categories in order to capture the full spectrum of functioning from mild to severe.

Why these Questions?

Disability represents a complex process and is not a single, static state. It refers to the outcome of the interaction of a person and their environment (physical, social, cultural or legislative) and represents a measure of the negative impact of environmental factors on one's ability to function. The complexity of the concept has resulted in the proliferation of statistics on disability that are not comparable and are difficult to interpret. Furthermore, disability data are collected for different purposes such as to estimate the prevalence of physical impairments or plan for the provision of services. Each purpose elicits a different statistic and even when the intent is to measure the same concept the actual questions used 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 central importance of the issue of social participation and equal rights from a policy perspective as illustrated by the UN Convention. In addition, there was agreement that it would be possible to develop a question set that could be administered using Census methodology and had the best chance to produce internationally comparable data.

One approach to measuring social engagement is to ask directly if a disability has impacted participation. An example of such a question is "Are you limited in the kind or amount of work you can do because of an impairment or health problem?" Such questions are difficult to ask in a way that produces comparable data. An alternative approach is to obtain information on difficulty in functioning in basic actions since these actions form the building blocks for more complex activities and, when restricted by the environment, can result in disparities in participation. The task is then to determine whether persons with difficulties or limitations in basic actions have participation rates equal to those without these limitations.

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.

The WG questions were designed to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources. The objective was to identify persons with similar types and levels of limitations in basic actions regardless of nationality or culture. While the ideal would be to collect information on **all** aspects of the disablement process 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. The basic actions represented in this question set 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. It is expected 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 actions, b) represent the most commonly occurring limitations in basic actions, and c) be able to capture persons with similar problems across countries.

How to Use the Data

The recommended set of questions identifies the population with difficulties in functioning in basic actions that have the **potential** to limit independent participation in society. The intended use of these data is to compare levels of participation in, for example, employment, education, or family life for those with disability versus those without disability and thereby to assess equitable access to opportunities as mandated by the UN Convention. In addition, the data can be used to monitor prevalence trends for persons with limitations in the specific basic action domains.

The WG recognizes that the short set of questions for censuses may not meet all the needs for disability statistics, nor will it replicate a survey of the population that can collect information across a wider range of disability domains. A census can provide valuable information on disability especially for local areas but other data collection mechanisms are necessary to obtain a more complete understanding of disability nationally and internationally. The WG is currently developing question sets for use on surveys.

The Washington Group on Disability Statistics

The Washington Group on Disability Statistics (WG) was organized in 2001 following the United Nations International Seminar on Measurement of Disability to address the need for statistical and methodological initiatives at an international level to facilitate the measurement of disability and the comparison of data on disability cross-nationally. To date, the WG has met seven times, in: Washington DC, USA (2002); Ottawa, Canada (2003); Brussels, Belgium (2004); Bangkok, Thailand (2004); Rio de Janeiro, Brazil (2005); Kampala, Uganda (2006); and most recently in Dublin, Ireland (2007). All National Statistical Offices are eligible for membership in the WG. Currently, 77 National Statistical Offices are represented, as well as 7 international organizations, 6 organizations that represent persons with disabilities (DPOs), the UNSD, and 3 other UN affiliates. The Secretariat for the WG is located at the National Center for Health Statistics (NCHS), USA. The main objective of the WG is the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys.

Details of the WG organization, history and accomplishments are available online at: (http://www.cdc.gov/nchs/washington_group.htm). In addition the site provides access to lists of participants, proceedings from the meetings (presentations and papers), reports to the UN Statistical Commission and information on upcoming meetings.

Building Capacity For Disability Data Collection In Developing Countries: Several government statisticians from developing countries have been trained on disability measurement methodology through the WG efforts. Regional training meetings held in Kenya (June, 2005) and Brazil (September, 2005) were an integral part of this effort. Presently, countries that received training are working internally to improve their overall approaches to dealing with the issue of disability measurement through ongoing data collection activities.

Fostering International Cooperation: The WG has cooperated with the United Nations Statistics Division (UNSD), the World Health Organization (WHO), the Statistical Office of the European Communities (Eurostat), the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), the United Nations Economic and Social Commission for Western Asia (UNESCWA), the International Labor Organization (ILO), the Budapest Initiative group, the World Bank and others to promote a unified approach to disability measurement. Several World Bank data instruments have been heavily influenced by the work of the WG, and related disability questions are currently being tested as part of the Living Standards Measurement Study (LSMS).

Future Work: The WG remains active and will continue to work on the development and testing of extended question sets for surveys and survey modules and the production of technical reports on methodological issues such as dealing with special populations (e.g., children and institutionalized persons). If resources allow, it also plans to continue to offer technical assistance to countries to build capacity for disability measurement and analysis.