

Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 9th Annual Meeting

Purpose

The main purpose of the Washington Group on Disability Statistics 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 which will provide basic necessary information on disability throughout the world. More specifically, the Washington Group aims to guide the development of a small set or sets of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, for the primary purpose of informing policy on equalization of opportunities. The second priority of the Washington Group is to recommend one or more extended sets of survey items to measure disability, or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items are intended to be related to the general measure(s). The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) has been accepted as the basic framework for the development of the sets. All disability measures recommended by the group, general or extended, will be accompanied by descriptions of their technical properties and methodological guidance will be given on their implementation and their applicability to all sections of the population. The Washington Group will disseminate work products globally through the World Wide Web.

Year organized

2001

Participants

Representatives of national statistical offices, international organizations, and non-government organizations have participated in the last 9 meetings.

Current representatives from national statistical authorities include 109 countries and territories: Albania, Argentina, Armenia, Aruba, Australia, Austria, , Bangladesh, Barbados, Belgium, Bermuda, Bolivia, Botswana, Brazil, Bulgaria, Burundi, Cambodia, Canada, Chile, China, Hong Kong Special Administrative Region of China, Macao Special Administrative Region of China, Columbia, Côte d'Ivoire, Cuba, Curacao, Cyprus, Czech Republic, Democratic Republic of the Congo, Denmark, the Dominican Republic, Egypt, Estonia, Fiji, Finland, France, Gambia, Ghana, Greece, Guatemala, Hungary, India, Indonesia, Iran, Iraq, Ireland, Israel, Italy, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Kuwait, Kyrgyz Republic, Lao, Latvia, Lebanon, Lesotho, Lithuania, Luxembourg, Malawi, Maldives, Malta, Mauritius, Mexico, Micronesia, Mongolia, Mozambique, the Netherlands, New Zealand, Norway, Oman, Pakistan, Occupied Palestinian Territory, Panama, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Romania, Rwanda, Saint Lucia, Serbia and Montenegro, Sierra Leone, Singapore, the Slovak Republic, Slovenia, South Africa, Spain, Sri Lanka, Sweden, Syria, Tanzania, Thailand, Tonga, Trinidad, Turkey, Tuvalu, Uganda, United Arab Emirates, United Kingdom of Great Britain and Northern Ireland, United States of America, Uruguay, Venezuela, Viet Nam, Zambia, and Zimbabwe. In the past,

the Bahamas, Comoros, Costa Rica, Ecuador, Nigeria, Tunisia, and the Turks and Caicos Islands also participated.

Past and present representatives of international organizations representing persons with disabilities (DPO) include the European Disability Forum, Rehabilitation International, the Inter-American Institute on Disability, the African Rehabilitation Institute, and the International Federation for Spina Bifida and Hydrocephalus. Past and present representatives of national DPOs include the National Disability Authority in Ireland, Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência (CORDE) in Brazil, Secretaria Nacional para la Integración de las personas con Discapacidad (SENADIS) in Panama, Disabled Organization for Legal Affairs and Social Economic Development (DOLASED) in Tanzania, Association Pro Personas Con Paralisis del Parque in Mexico, the Puerto Rico Council on Developmental Disabilities, the Office of the Ombudsman for People with Disabilities in Puerto Rico, the National Institute on Disability and Rehabilitation Research in the United States of America, and the National Union of Persons with Disabilities of Uganda (NUDIPU).

Other international organizations that have previously or currently participate in the Washington Group include EUROSTAT, Partnership Health EU, the International Labor Organization, the Organization for Economic Cooperation and Development, the Inter-American Development Bank, the International Development Project, the World Bank, the World Health Organization, World Health Organization Family of International Classifications Collaborating Center, the United Nations Economic and Social Commission for Asia and the Pacific, the United Nations Economic and Social Commission for Western Asia, the United Nations Economic Commission for Europe, and the United Nations Statistics Division.

Past meetings/major outcomes

First meeting: Washington, D.C., 18-20 February 2002

It was agreed that: 1) it is important and possible to craft a short set/s of internationally comparable disability measures; 2) short and long set(s) of measures that are inter-related are needed; 3) the ICF model will be used as a framework in developing disability measures; and 4) census questions are the first priority.

Second meeting: Ottawa, 9-10 January 2003

A link was established between the purpose/s of a short measure on disability and aspects of measurement. A conceptual matrix was developed linking the purpose of a short disability measure with conceptual definitions and question characteristics. An empirical matrix was developed evaluating the characteristics of short set(s) of disability measures currently in use according to the dimensions of the conceptual matrix. Both matrices helped the WG to identify gaps in disability measurement.

Third meeting: Brussels, 19-20 February 2004

Since disability is multidimensional, it is not possible to ascertain the single “true” disabled population. Different purposes are related to different dimensions of disability or different conceptual components of disability models. Equalization of opportunities was selected as the purpose for which an internationally comparable short disability measure would be developed. A workgroup was designated to generate a draft set of questions related to this purpose. In addition, two other workgroups were formed to propose methods for implementing the short set and to propose an approach for developing extended measurement sets related to the short set. Finally, a plan for WG governance was adopted.

Fourth meeting: Bangkok, September 29-October 1, 2004

Major outcomes of the 4th WG meeting were: 1) conceptual agreement on a draft set of questions for the general disability measure, but wording revisions were required prior to pre-testing; 2) formation of a new workgroup operating in conjunction with a consultant to develop six implementation protocols for pre-testing the short set of disability measures; 3) begin development of the first extended measurement set; and 4) formation of a new workgroup on methodological issues.

Fifth meeting: Rio de Janeiro, 21-23 September 2005

Revisions were suggested for the short measurement set, the accompanying rationale, and the implementation protocols. A new workgroup was formed to plan and implement analyses of the WG pre-tests. All results pertaining to the six WG questions will be considered by the new workgroup including the WG sponsored pre-tests, the WHO/ESCAP test, and other testing activities.

Sixth meeting: Kampala, October 10-13, 2006

Based on the outcomes of the pre-tests, the WG endorsed the six question set for use in censuses. The set comprises questions on four core functional domains (seeing, hearing, walking, and cognition) as well as two additional domains desired by member countries (self care and communication).

Detailed analyses of the pre-test data were presented at the meeting, however as there was much more analytical work that can be done that would be informative, the methodological workgroup merged with the data analysis workgroup to address three specific issues:

- 1) Portability of questions across administration modes;
- 2) How the questions work for specific subpopulations such as those with severe disability, children, or the institutionalized population; and
- 3) The use of proxy informants.

The workgroup on extended measures was charged with self-organizing in order to accomplish their work, and drafting a position paper specific to developing the first extended set with a

purpose of equalization of opportunities. The paper was to include a plan and approach (blueprint) for carrying out development of the extended set including the purpose, rationale, and justification for the extended set as well as the issue of international comparability. The group was charged with adding questions on the existing domains and adding domains as appropriate to assess equalization of opportunities. The group was to review and select existing questions and pre-test the question set if time permits.

Seventh meeting: Dublin, September 19-21, 2007

The workgroup on the short set addressed the use of the short set as a screener and presented an alternative (optional) question on upper body function. The combined workgroup on data analysis and methodological issues provided further analyses of the pre-test data presented at the 6th meeting. A large part of the seventh meeting was dedicated to a discussion of work being done on the extended set of disability questions for surveys and survey modules. A proposal to develop an extended question set for the purpose of assessing equalization of opportunities was presented by the extended sets workgroup.

The Extended Sets Workgroup was charged with re-visiting the single Short Set questions and adding multiple questions to certain domains that examine the use of assistive technology and functioning with and without assistance; adding questions on other domains including upper body functioning, learning, affect, pain and fatigue; deciding on the inclusion of supplementary questions within domains (cause, onset, duration, etc.); deciding on how best to capture environmental factors (micro, meso, and macro levels); and exploring different ways to measure participation. The Workgroup would coordinate its work with the work of the BI, Eurostat, and UNESCAP; and compile lists of questions being used in other groups and by countries internationally.

Eighth meeting: Manila, October 29-31, 2008

The Extended Set workgroup was charged with developing an extended question set (or sets) for use in surveys and survey modules with the intended purpose of assessing equalization of opportunities. It was agreed that as a first step this workgroup would address expanding upon the set of domains already covered in the short set, adding supplementary questions within domains (cause, age at onset, duration), begin a discussion on how best to capture environmental factors and explore different ways to measure participation. Development of the extended set/s was to be done in collaboration with the Budapest Initiative, Eurostat and UNESCAP.

Methodological issues were raised during the eighth meeting concerning the development of questions for children and institutionalized populations and the use of proxy respondents. WG representatives from Canada and France volunteered to look at the work being done in the areas of children and institutionalized populations, respectively, within their regions and prepare reports to be presented at the 9th WG meeting. The group is hopeful that some of the issues related to use of proxy respondents will be raised during the field testing of the proposed extended sets of question.

Report of the Ninth meeting: October 7-9, 2009 in Dar es Salaam, Tanzania

The ninth meeting was hosted by the Tanzanian National Bureau of Statistics (NBS). The meeting was attended by 64 persons;

- 36 representing national statistical authorities from 18 countries (Bangladesh, Burundi, Cambodia, Canada, Czech Republic, Egypt, Italy-2, Kazakhstan, Kenya, Lesotho, Mongolia, Mozambique, Philippines, Rwanda, Sri Lanka, Tanzania-18, Uganda, and Zimbabwe);
- 4 representatives from the National Center for Health Statistics;
- 10 representatives from national institutes of public health or other national research bodies or ministries (China, France, Ireland, Korea, Maldives, Oman-2, South Africa, Tanzania and United Arab Emirates);
- 2 representatives from the United Nations Economic and Social Commission for the Asia and the Pacific (UNESCAP);
- 2 representatives from the United Nations Children's Fund (UNICEF);
- 1 representative from the United Nations Economic Commission for Europe (UNECE);
- 1 representative from the European Disability Forum; and
- 8 representatives from local organizations, institutes of public health or other local research bodies

Objectives for the 9th WG meeting were to:

1. Present additional work on Extended set questions
2. Present Cognitive/Field test results and data analysis
3. Discuss special methodological considerations:
 - Children with disabilities
 - Institutionalized populations
4. Discuss strategic issues

The Matrix that guided the development of Extended set questions was introduced at the eighth meeting in Manila. A draft of the Extended set questions and plans for cognitive and field testing of the questions were also presented in Manila. Both of these documents were revised, edited and updated after the Manila meeting and in preparation for the anticipated cognitive and field testing. The revised Matrix was re-introduced at the ninth meeting and the meeting then focused primarily on the presentation and discussion of results from the cognitive test results and preliminary field tests results.

Cognitive and Field Testing

Training for the Cognitive and Field Testing of the proposed Extended Sets took place February 16 – 20, 2009 in Bangkok, Thailand. The combined testing exercises were carried out in collaboration with UNESCAP. Six UNESCAP countries participated in the cognitive/field testing workshop: Cambodia, Kazakhstan, Maldives, Mongolia, Sri Lanka and Philippines. Subsequent cognitive testing took place in these countries as well as Canada, the United States, and South Africa. For the cognitive testing phase, participating countries were asked to conduct

approximately 20 interviews. After the interviews were completed, the interview data was entered into Q-Notes, an on-line data entry and analysis tool.

The goals of the cognitive test included determining:

- How do the respondents understand the survey question?
- Do respondents in different countries understand the survey question differently?
- Does the question mean the same in all the languages that it is asked?
- Does the question mean the same in all of the cultures that it is asked?
- In processing a question, do all respondents recall information and form an answer the same way?
- What groups should be considered for comparability?

Following the completion of the cognitive testing, a small group met at the National Centers for Health Statistics in Hyattsville, Maryland (USA) in May 2009 to discuss the preliminary analysis of the cognitive testing results. The group identified the ways in which each question performed among different respondents. The results from the cognitive test results were used to inform the field tests.

Following the cognitive testing phase, field testing took place in the six UNESCAP countries. A sample of approximately 1,000 interviews from each country was recommended for the field tests. Children over 5 years of age were eligible for inclusion in the sample and proxy respondents were to be used for all children under 18 years of age were to be interviewed by proxy. The overall intent of the field tests was to understand the extent to which the performance of each question differs across respondents.

The main objectives of the field testing were to test:

- the relationship between the WG Short and Extended Sets
- cross country comparability
- the hypotheses arising from cognitive testing and the translation

At the ninth meeting, for each domain the question set used in the cognitive test was presented. This was followed by a discussion of the results of the cognitive test and how these results impacted on the development of a field test instrument for that domain. Preliminary results from the field tests in two of the participating UNESCAP countries (Maldives and Sri Lanka) were presented. A representative from each of the six UNESCAP countries provided their experiences with the either cognitive or the field test.

The overall conclusion was that further analysis of the field test data was required before a final decision could be made regarding the extended set of questions.

Methodological Issues Concerning Surveys

Methodological issues concerning the development of questions for children and institutionalized populations were raised at the eighth meeting. WG representatives from Canada and France volunteered to look at the work being done in the areas of children and institutionalized populations, respectively, within their regions and prepare reports for presentation at the 9th WG meeting.

At the ninth meeting, the representative from France provided a presentation on the impact of including or excluding the institutionalized population when calculating disability population estimates. The goal of her analysis was to determine if disability statistics currently being collected were representative of the entire population. In Europe, administering surveys within institutions is very difficult. The health of the population is measured by health surveys that are mainly based on the household population. Through her analysis, the representative from France hoped to determine if it is beneficial to develop surveys that could be administered in institutions for comparison. She looked at two approaches that have previously been used to calculate the prevalence of disability in Europe. The first approach is based on the Sullivan model that uses an aggregate health indicator to estimate the disability free life expectancy. Sullivan makes the assumption that living in an institution is an expression of disability and suggested that the prevalence of disability among the institutionalized population should be 100% (Sullivan, 1971).

The second approach is based on Eurostat's calculation of Healthy Life Years (HLY). This calculation is based only on the prevalence of disability among the household population and assuming that the same prevalence would be observed for the population outside the household. The outside the household population consists of two groups: individuals living in collective households and individuals residing in nursing or health care institutions.

Population data from 2000 collected by Eurostat were used to look at the population distributions for 13 countries (Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Lithuania, and the Netherlands). The population living outside of households ranged from 3.5% in Greece to less than 1% in Italy and Cyprus. There was a large variation in the composition of the population living outside of the household based on age group distributions of this population among the countries. In some countries there was a larger proportion of children/youth living outside the household in collective households (e.g. boarding schools). In other countries the population composition of those living outside the household was driven by the elderly living for the most part in institutions. Using data on activity limitations collected by Eurostat, disability prevalence was calculated using both approaches and the results were compared. It was determined that Eurostat's calculations overestimated the HLY in comparison to Sullivan's approach.

The following conclusions were made from the analysis:

- 1) Based only on household information, population estimates are underestimating the prevalence of disability. The magnitude of the bias depends on the age patterns among those living in institutions outside of the household and the type of disability under consideration.
- 2) Sullivan's assumption appears to be more accurate, but only when focusing on health related institutions.
- 3) The variation of the proportions and type of institutions across Europe prevents researchers from applying Sullivan's assumption.
- 4) The reality is in between the two assumptions, giving the two limits of a range for the estimates.
- 5) An approach that combines both methods can be useful to better estimate population disability prevalence and avoid conducting worldwide surveys in institutions.

Based on the information presented, the group concluded that, at this time, it was beyond the scope of the WG to address the issue of dealing with institutionalized populations. This issue will be revisited in the future.

Representatives from Canada and the USA presented an overview of national efforts to measure disability among children in their respective countries. Canada presented the results of the 2006 Participation and Activity Limitation Survey (PALS) that reported a disability prevalence of 3.7% among children 0-14 years of age. Furthermore, the survey found that the rate of false positive responses to Census filter questions is very high in comparison to adults (about 20% for adults and 50% for children); and that the small sample size for survey makes the results less useful.

The representative from the USA presented some work that had recently been completed that operationalized a measure of basic actions difficulty based on the work of Altman and Bernstein (2008) in *Disability and Health in the United States, 2001 – 2005*. This approach produced a prevalence rate of 18% - described as those at greater risk than the general population of experiencing restricted participation in society (in, for example, employment, education or family/civic life).

Based on these initial presentations it was decided that a workgroup be constituted that would look more closely at the measurement of child disability and report back to the WG at its 10th meeting. The representative from Canada offered to lead this workgroup.

Barbara Altman (USA) prepared a paper and a presentation that described some of the challenges in measuring environmental factors in an international context. In particular, it was pointed out that cultural elements of environment should be assessed and included when attempting to create universal measures of environmental barriers and facilitators to participation.

It was decided that a workgroup be formed to look more closely at the development of a set of questions on environmental factors as they relate to the measurement of disability. Barbara Altman agreed to lead this workgroup and present an update at the 10th meeting in Luxembourg.

Country Reports

A summary of the annual reports on national activities related to disability statistics was provided. Annual reports were completed by 46 countries. The information provided included usage of the WG Short Set of questions in recent data collection activities and plans for their use in the upcoming round of censuses. The primary representatives from 21 countries indicated that the short set of questions would be included in their upcoming census round. For countries indicating the short set of disability questions would not be used in the upcoming census round, the reasons for not using the questions included:

- Washington Group questions were not finalized when census questions were decided
- Required to use the same questions that were used in previous census rounds
- Too expensive to add additional questions to census
- Too many questions; the number of disability question allowed on the census is restricted
- Respondents had trouble understanding questions during pretest
- Concerns regarding the Washington Group short set answer categories

Documents for Consideration

Two documents drafted by members of the WG Secretariat and Steering Committee were circulated among the delegates for review and comments. The first document is a paper on understanding and interpreting disability as measured using the WG Short Set of Questions. This document was originally presented as a draft paper at the eighth meeting and has since been finalized. The second paper was drafted at the request of several WG representatives and concerns the application of the WG Short set of questions in the up-coming round of censuses. The paper addresses the issues of adapting to regional, cultural context and training. Participants were encouraged to review the documents and submit any comments or questions to the WG Secretariat. Copies of the documents mentioned can be obtained by contacting the WG Secretariat

Updates on other Washington Group and collaborative activities

The Washington Group continues to collaborate with the UN Economic Commission for Europe, WHO, and Eurostat on the Budapest Initiative (Task Force on the Measurement of Health Status). At a meeting held in Geneva in June 2009, the collaborative efforts of the Washington Group and the Budapest Initiative in developing extended sets of questions for use as components of population surveys, as supplements to surveys or as the core of a disability survey were presented. The testing of these questions has been supported by UN Economic and Social Commission for Asia and the Pacific (ESCAP). UNESCAP has provided the funding for the cognitive and field testing of the extended question sets developed by the Washington Group/Budapest Initiative collaboration.

A small group from the Secretariat met with World Bank representatives at the Bank in Washington DC in May 2009. The group discussed the work of the WG and the possibility of the World Bank providing funding for future WG activities. A proposal was submitted for funding to replicate projects similar to the UNESCAP project in other regions. The World Bank

had not responded to the proposal at the time of the ninth meeting. Country representatives were encouraged, however, to contact their World Bank regional offices, regional banks, and health ministries regarding support and funding for disability data collection activities within their countries and regions.

Key agreements of the 9th meeting and next steps:

At the ninth meeting, the Washington Group agreed to its work plan for 2010. Among other items, the plan delegates specific responsibilities to working groups that meet throughout the year (via email and telephone conferences). Next steps for the workgroups include:

1. Work on the extended sets of questions for surveys
 - continued analysis of the field test results through the first half of 2010
 - expansion of cognitive and field testing of the extended set of questions to other regions
 - in particular, Europe
 - results of data analyses from the completed field testing and additional cognitive testing to be presented at the 10th meeting of the WG in November 2010

2. Work on methodological issues
 - assess the applicability of the short set of questions for specific subpopulations such as children; determining the age at which the questions are meaningful by evaluating the test data from children; developing specific question modules for children
 - design extended set questions for the measurement of environmental factors including both barriers and facilitators
 - status reports from the work groups on measurement of child disability and environmental factors to be presented at the 10th meeting of the WG
 - evaluate the proxy data from the field tests

It was strongly recommended by the delegates, particularly those from African countries, that projects similar to the one funded by UNESCAP in the Asia and Pacific region, also be established in other regions. It was further suggested that funding assistance be sought from UNSD, regional commissions, other UN agencies, and regional development banks to meet this request.

Objectives for the 10th WG meeting:

- Present additional work on extended set:
 - results of data analyses from the completed field testing
 - update on expansion of cognitive and field testing of the extended set of questions to other regions and presentation of results (if any)
 - update on any revisions to extended set questions
- Present status reports from the work groups on measurement of child disability and environmental factors and the use of proxy respondents
- Discuss strategic issues.

Governance issues

The 10th WG meeting will be held November 2010 in Luxembourg.

In keeping with UN guidelines, issues of gender bias and other potential sources of bias will be a consideration of all WG work.

Products:

Proceedings from the meetings (presentations and papers), reports to the UN Statistical Commission, final meeting reports, and information on upcoming meetings can be accessed through the Washington Group website, currently hosted by the National Center for Health Statistics, U.S.A. (http://www.cdc.gov/nchs/washington_group.htm).

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