

Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 8th 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 8 meetings.

Current country representatives include (from national statistical offices): Albania, Argentina, Australia, Austria, Armenia, Barbados, Belgium, Bermuda, Bolivia, Brazil, Cambodia, Canada, Chile, China (Hong Kong Special Administrative Region, Macao Special Administrative Region, and Mainland), Columbia, Cuba, Czech Republic, Democratic Republic of Congo, Denmark, Egypt, Finland, France, Gambia, Ghana, Greece, Guatemala, Hungary, India, Iran, Iraq, Ireland, Israel, Italy, Ivory Coast, Japan, Jordan, Kenya, Latvia, Lebanese Republic, Lesotho, Lithuania, Malawi, Mauritius, Mexico, Micronesia, Mongolia, New Zealand, Norway, Occupied Palestinian Territory, Panama, Paraguay, Peru, Philippines, Poland, Romania, Serbia and Montenegro, Sierra Leone, Slovenia, South Africa, Spain, Saint Lucia, Sweden, Syria, Tanzania, Thailand, The Netherlands, Turkey, Tonga, Trinidad, Uganda, United Kingdom of Great Britain and Northern Ireland, United States of America, Venezuela, Viet Nam, Zambia, and Zimbabwe.

Current non-government organizations include: European Disability Forum, Rehabilitation International, Inter-American Institute on Disability, EUROSTAT, International Labor Organization, Organization for Economic Cooperation and Development, National Disability

Authority-Ireland, Inter-American Development Bank, International Development Project, World Bank, World Health Organization, United Nations Economic and Social Commission for Asia and the Pacific, United Nations Economic and Social Commission for Western Asia, United Nations Economic Commission of Europe, and United Nations Statistics Division.

Governmental Organizations of Persons with Disabilities: 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, and Disabled Organization for Legal Affairs and Social Economic Development (DOLASED) in Tanzania.

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.

Extended Sets workgroup tasks:

- Re-visit the Short Set of basic activity (functioning) domains (adding possibly multiple questions to certain domains)
- Decide on the use of an upper body domain
- Decide on the inclusion of supplementary questions within domains (cause, onset, duration, etc.)
- Decide on how best to capture environmental factors (micro, meso, and macro levels)
- Explore different ways to measure participation
- Coordinate work with the work of other groups (BI, Eurostat, UNESCAP)
- Compile list of questions being used in other groups
- Determine timeline for extended set
- Determine who wants to be involved in the Extended Sets Workgroup. (Margie Schneider, chair)

Report of the Eighth meeting: October 29-31, 2008 in Manila, Philippines

The eighth meeting was hosted by the Philippine National Statistical Coordination Board (NSCB) and the Philippine National Statistics Office (NSO). The meeting was attended by 54 persons;

- 24 representing national statistical authorities from 18 countries (Bangladesh, Brazil, Cambodia, Canada, Fiji, India, Ireland, Israel, Italy-3, Mongolia, Philippines-5, Singapore, Spain, Sri Lanka, Tanzania, Uganda, Viet Nam and Zimbabwe);
- 3 representatives from the National Center for Health Statistics;
- 10 representatives from national institutes of public health or other national research bodies or ministries (France, Indonesia, Ireland, Japan, Kenya, Maldives, Oman, South Africa and United Arab Emirates-2);
- 4 representatives from the United Nations Economic and Social Commission for the Asia and the Pacific (UNESCAP)
- 13 representatives from local organizations, institutes of public health or other local research bodies

Objectives for the 8th WG meeting were to:

1. Present a proposal for extended set questions.
2. Discuss WG activities and overlap with the work of other disability data collection initiatives
3. Discuss special methodological considerations
 - Children with disabilities
 - Institutionalized populations
4. Discuss strategic issues

Objectives for the eighth meeting emanated from work presented at the seventh meeting. 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.

Extended Sets Workgroup

A small working group consisting of members from the Washington Group (WG) and Budapest Initiative (BI) met for 3 days in July 2008 at the National Center for Health Statistics (NCHS) in Hyattsville, MD. The goal of this meeting was to draft a proposed set of extended questions to be presented at the 8th WG meeting in the Philippines. The initial approach taken by the workgroup was to expand on the 6 domains (Vision, Hearing, Cognition, Mobility, Self Care, and Communication) addressed in the WG Short Set. The focus was to look at questions that already existed and determine how the WG work was related to the work of other groups: Budapest Initiative (BI), Eurostat, and UNESCAP. At this meeting, a “Matrix”, designed as a framework for the development of the extended questions, was presented.

At the 8th WG meeting in Manila representatives from the workgroup provided the outcomes from the July meeting including an overview the “Matrix” and the proposed set of extended questions. The presentation included outlining the rationale and framework used to develop the extended question sets. Group work and discussions at the 8th meeting provided feedback on the issues/problems with each extended set question and/or answer categories that were identified. As part of the presentation and discussion each of the proposed questions was reviewed in detail. The strengths and limitations of asking each question and corresponding answer categories as proposed were debated. In many cases, the conclusion was that multiple versions of the questions should be tested during cognitive and field testing.

Cognitive and Field Testing

Cognitive and field testing of the proposed extended sets are expected to take place in early 2009. The combined testing exercises will be done in collaboration with UNESCAP. Prior to country specific cognitive testing, interviewer training will take place in Bangkok (early 2009). For the cognitive testing phase, participating countries will be asked to conduct approximately 20 interviews. A small group will meet following the cognitive testing to conduct preliminary analysis of the results. Results from the cognitive tests will be used to inform the field testing. A sample of approximately 1,000 interviews is recommended for the field testing. Children over the age of 5 years old will be eligible for inclusion in the sample. Proxy interviews will be conducted for anyone under the age of 18 years of age.

The main objectives of the field testing are to test:

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

The results from both the cognitive and field tests will be documented and presented at the 9th meeting of the WG. Country representatives from national statistics offices were encouraged to volunteer to participate in the cognitive and field testing. (Postscript: the 7 countries participating in the testing include: Cambodia, Kazakhstan, Fiji, Maldives, Mongolia, Sri Lanka and Philippines.)

Methodological Issues Concerning Surveys

Methodological issues were raised concerning special populations, specifically the use of proxy respondents, and the development of questions for children and institutionalized populations. 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 questions.

Four documents drafted by members of the WG Secretariat and Steering Committee were circulated among the delegates for review and comments. The first two documents were developed to introduce the WG to Disabled Peoples' Organizations and National Statistics Offices. A separate paper was drafted for each audience. The third document concerns the applicability of the WG questions in monitoring the UN Convention on the Rights of Persons with Disability. The fourth document is a draft paper on understanding and interpreting disability as measured using the WG Short Set of Questions. 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

UNESCAP: Representatives from the UNESCAP Statistics Division provided a presentation on the improvement of disability measurement in support of BIWAKO Millennium Framework for Action and the Regional Census Programme. The framework was designed to promote an inclusive, barrier-free and rights-based society for people with disabilities in the Asian and Pacific region.

The ESCAP project originated in response to policy initiatives that call for better disability statistics and a unified regional approach to data collection and analysis.

Plans to address country specific needs for support would include:

- Further promoting the ICF approach among all stakeholders
- Promoting data collection through 2010 round of Censuses
- Developing standards for survey-based data collection
- Targeted training, technical assistance and advisory services
- Knowledge-sharing; regional network of experts

ESCAP would work in close partnership with the Washington Group and other organizations including the United Nations Statistics Division (UNSD), United Nations Economic Commission for Europe (UNECE), World Health Organization (WHO), Budapest Initiative and National Statistics Offices (including Australia and Philippines).

The project hopes to raise awareness through regional and in-country workshops. Another goal is to develop regional standards for pilot testing and analyzing results.

Key activities of the project include:

- Regional workshop on census data collection
- Develop standard survey question sets
- Pilot test in 7 countries (Cambodia, Kazakhstan, Fiji, Maldives, Mongolia, Sri Lanka and Philippines.)
- Joint result analysis and formulation of recommendations
- In-country advocacy & advisory services
- Targeted Training
- Knowledge management tools

(The cognitive and field testing exercises mentioned above are part of these activities.) ESCAP will serve as the managing partner. The Steering Committee will oversee the design and implementation. The work will be completed by task teams headed by the leading experts in the field. The countries involved in the pilot test will present a joint report of their analysis at the 9th meeting of the WG. The information obtained from the pilot testing will be used to inform WG extended question set development.

Budapest Initiative: The Budapest Initiative has agreed to work in collaboration with the WG in areas of the extended question sets that overlap. A BI taskforce meeting is scheduled in February 2009. During this meeting, results from the cognitive testing may be presented if available.

World Bank: Due to changes in personnel at the World Bank recent activity with respect to the WG has been somewhat curtailed. Country representatives were encouraged to contact their World Bank regional offices regarding support and funding for disability data collection activities within their countries and regions.

WHO-FIC Network – Washington Group Bridging Task Group: A Bridging Task Group has been formed, comprised of members of the Functioning and Disability Reference Group (FDRG) and WG. The main objective of the Task Group is to propose means of cooperation and knowledge transfer between the FDRG and the WG, so as to add value to each other's work, promote shared goals, and avoid undesirable overlaps or inconsistencies. The group has primarily met via teleconference. There has been one face to face meeting in Quebec City in August 2008.

Country Reports

A summary of the annual reports on national activities related to disability statistics was provided. Annual reports were completed by 43 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.

Country Experiences

Presentations were given followed by discussion on the following topics:

1. Comparing disability rates from the 2006 Irish Population Census and the Ireland's National Disability Survey (NDS).

A representative from the Irish CSO presented some preliminary results comparing disability measurements from the 2006 Irish Census and the National Disability Survey and detailed NDS findings on disability types and difficulty profiles of disabled in Ireland.

They found a high consistency between NDS and Census in terms of identification of disability. A small number of persons who had no disability in the Census indicated a disability in the NDS. Inclusion of these persons in the prevalence rate would increase it from the 9.3% recorded in the Census to 18.5% (after excluding persons who had a disability in the Census who did not have a disability in the NDS).

They also found that prevalence rates were subject to the influence of the level of difficulty scale (Census used a Yes/No response while the NDS employed a 5 point scale), range of explicit disabilities (for *long-lasting conditions* the Census includes a category *other/chronic illness*; and for *difficulties experienced* the NDS includes the domains *speech, pain* and *breathing*) and data collection methodology (Census versus survey).

More specifically, while 33% of persons with a disability in the Census Disability Sample had a moderate or lower level of difficulty, that number rose to 47% in the combined sample (Census Disability Sample and General Population Sample). They conclude that in a Census disability question that has Yes/No response options, respondents should be instructed to consider a moderate level of difficulty as a disability.

Finally they conclude that, according to their results and unless specifically targeted, a short question set is more likely to miss out on children, persons aged 35-44 and on persons with Pain and Breathing disabilities depending on domain coverage.

2. Disability in the 2000 Brazilian Census

A representative from the Population Census Committee in Brazil presented background and results from the 2000 Census with respect to issues of disability. Of relevance to the Brazilians were the following topics:

1. Why to include this topic in a population census?
2. Why it was considered necessary to have more than one question in the census form?

3. Screening questions: problems when using them for disability topics
4. False negatives and false positives
5. Minimum number of questions in the census
6. Domains Chosen
7. Degrees of severity
8. What can be asked and what cannot be asked
9. Cognitive tests and joint pilot test

Proposals for the 2010 Census were also presented. Cognitive testing of the proposed questions was carried out on April 2006 in three Brazilian municipalities.

- Selection Process:
 - Information on disabled people collected from the 2000 Census was used to identify the sample of selected households
 - Quota Sample of each domain tested
 - Selected Census Tracts with higher density of disabled people
- A set of additional disability questions was used to measure consistency with the core questions. Generally results were consistent.
- When compared with the 2000 Census, responses were also compatible, but seemed to detect better some types of problems
- There were no problems encountered in understanding the core questions
- The questions did not perform as well for children with mental retardation or other problems
- Small proportion of false-negatives or false-positives

3. Assessing the consequences of chronic diseases on functional health (France)

A representative from the Institut National d'Études Démographiques (INED) Research Unit in France presented results of research exploring the associations between chronic diseases and functional health defined in terms of basic activity or functional limitations (e.g. vision, hearing, mobility etc.) and participation restrictions (measured in terms of ADLs and IADLs).

Using logistic regression models and controlling for age and sex, the research looked at associations among potentially disabling chronic conditions, functional limitations and participation restrictions. They included in their analyses measures of health care utilization (number of visits to hospital or physicians), self-perceived health, administrative assessment of disability status and pain.

Through their analyses they determined that there are different disability experiences: some appear to be more self-perceived / others more visible (mental diseases, malformations, disabling nervous diseases); and that there are different 'causes' for these experiences. They may be explained by the associated functional limitations – "body function alterations" (e.g. weight problems, deafness, and some traumas), or explained by functional limitations and co-factors (circulatory and respiratory diseases) / or only partly explained (e.g. degenerative diseases, diabetes, osteoarthritis, malformations); or explained by co-factors only (strabismus, skin

diseases) / only partly explained (some cancers, epilepsy). They conclude that it is possible to describe each disease in terms of the associated disability experience and its determinants.

Potential Funding Opportunities

An overview of the European Union's (EU) 7th Framework Programme was provided and the opportunities it may offer in furthering WG objectives through funded research. The 7th Framework Programme is the main financial tool through which the European Union supports research and development activities covering almost all scientific disciplines.

Potential benefits to the WG:

- Sustain the scientific progress of disability statistics
 - Through country specific training and human resources development (cognitive testing; field testing)
 - Through the further development of extended questions (cognitive testing; field testing)
- Upscale the scientific progress of disability statistics
 - The scale of funding would allow for multiple countries to advance disability statistics at one given time period

Participation Potential for WG:

- The current call for research proposals:
 - allows for participation of high income countries outside of EU/EEA
 - allows for participation of international cooperation partner countries from all parts of the world;
 - allows for participation of international agencies;
- A minimum of five partner countries are required;
 - Two European Union (including Associated Countries)
 - Three from each of the other regions (Asia Pacific, Latin America, Africa)
- Number of partner countries is not limited
- Each partner could facilitate work in a number of different countries in their respective region (act as regional nodes);
- One partner would coordinate the overall project (EU/EEA/International Cooperation Partner Country)

As an existing United Nations City Group with a broad membership in all regions of the world and an established network, the WG could act as a catalyst to country inclusion and assist in the co-ordination of the project.

Conclusion: The group decided to take some time to think about participating in the program. The idea will be revisited in the future. WG Participants were asked to send comments to the WG Secretariat.

Key agreements of the 8th meeting and next steps:

- Work on a proposed set of extended questions will continue and a set will be finalized prior to cognitive testing in early 2009
- Cognitive testing training is planned for February 2009 to take place in Bangkok, Thailand. Under the sponsorship of UNESCAP, six countries have been designated to participate in the testing. Other countries were invited and encouraged to either participate in the UNESCAP sponsored training; or to undertake cognitive/field testing under the guidance of the WG.
- Analysis of cognitive testing to take place prior to field testing of the questions in order that the questions may be modified based on the cognitive test results
- Results of data analyses from both cognitive and field testing to be presented at the 9th meeting of the WG in October 2009

Objectives for the 9th WG meeting:

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

Governance issues

The 9th WG meeting will be held October 2009 in Tanzania.

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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