

Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 13th Annual Meeting

Purpose

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. The aim is to provide basic necessary information on disability which is comparable throughout the world. For the primary purpose of informing policy on equalization of opportunities, the WG has developed, tested internationally, and adopted a short set of disability measures suitable for use in censuses, sample-based national surveys, or other statistical formats.

A second priority is to recommend one or more extended sets of survey items to measure disability, or guidelines 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 short set of disability measures. The World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) has been used as the basic framework for the development of all questions sets. The disability measures recommended by the WG, both short and extended, are accompanied by descriptions of their technical properties, and methodological guidance is given on their implementation and their applicability to population subgroups. The WG disseminates its work products globally through the world-wide web and scientific publications.

Year organized

2001

Participants

Representatives of national statistical offices, international organizations, and non-government organizations including international disability organizations have participated in the last 13 meetings.

There are currently representatives from national statistical authorities in 118 countries and territories: Albania, Antigua and Barbuda, Argentina, Armenia, Aruba, Australia, Austria, Bangladesh, Barbados, Belgium, Bermuda, Bolivia, Botswana, Brazil, Bulgaria, Burundi, Cambodia, Canada, Chad, Chile, China, Hong Kong Special Administrative Region of China, Macao Special Administrative Region of China, Columbia, Côte d'Ivoire, Costa Rica, Croatia, Cuba, Curacao, Cyprus, Czech Republic, Democratic Republic of the Congo, Denmark, the Dominican Republic, Egypt, Estonia, Fiji, Finland, France, Gambia, Germany, 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, Morocco, Mozambique, the Netherlands, New Zealand, Norway, Oman, Pakistan, Occupied Palestinian Territory, Panama, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Romania, Rwanda, Saint Lucia, Sint Maarten, Saudi Arabia, Serbia and Montenegro, Sierra Leone, Singapore, the Slovak Republic, Slovenia, South Africa, Spain, Sri Lanka, Sweden, Syria, Tanzania, Thailand,

Tonga, Trinidad, Tunisia, 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, Ecuador, Nigeria, 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, the National Union of Persons with Disabilities of Uganda (NUDIPU), Age Concern Bermuda, Bermuda Resources for the Advancement of Children with Special Needs, Bermuda Autism Support & Education, Bermuda Government - Community Rehabilitation Occupational and Physiotherapy Services, Bermuda Government - National Office for Seniors and the Physically Challenged, Bermuda Government - Human Rights Commission, Bermuda Government - Department of National Drug Control, Bermuda Society for the Blind, Bermuda Hospitals Board, ADAPT (formerly The Spastics Society of India), and the International Disability Alliance (IDA).

Other international organizations that have previously participated or currently participate in the Washington Group include EUROSTAT, the European Union Agency for Fundamental Rights (FRA), 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 Children's Fund, 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

Agreement was reached on the following: 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 identify the single “true” disabled population. Different purposes for data collection 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, 29 September - 1 October 2004

Agreement was reached on the following: Conceptual agreement on a draft set of questions for the general disability measure, but wording revisions were required prior to pre-testing; a new workgroup operating in conjunction with a consultant to develop six implementation protocols for pre-testing the short set of disability measures was formed; agreement to start development of the first extended measurement set was reached; and a new workgroup on methodological issues was formed.

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, 10-13 October 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). The methodological workgroup and the data analysis workgroup merged to continue the detailed analysis of the pre-test data. The workgroup on extended measures was charged with drafting a position paper on the first extended set.

Seventh meeting: Dublin, 19-21 September 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 7th meeting was dedicated to a discussion of work being done on the extended set of disability questions for surveys and survey modules. The extended set workgroup would coordinate its work with the work of the Budapest Initiative, Eurostat, and UN ESCAP.

Eighth meeting: Manila, 29-31 October 2008

Work on the extended set continued by expanding upon the set of domains already covered in the short set, and adding supplementary questions within domains (cause, age at onset, duration). Development of the extended set/s was to be done in collaboration with the Budapest Initiative, Eurostat, and UN ESCAP. Methodological issues were raised during the 8th 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.

Ninth meeting: Dar es Salaam, 7-9 October 2009

The primary focus of the 9th meeting was the presentation and discussion of results from the cognitive tests and preliminary field tests results in South-East Asia. Preliminary results from the field tests in two of the participating UN ESCAP countries (Maldives and Sri Lanka) were presented. 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. It was concluded that it was beyond the scope of the WG to address the issue of dealing with institutionalized populations at that time. Two workgroups were constituted to look more closely at the measurement of child disability and the development of a set of questions on environmental factors as they relate to the measurement of disability. It was strongly recommended by the delegates, particularly those from African countries, that projects similar to the one funded by UN ESCAP in the Asia and Pacific region, also be established in other regions.

Tenth meeting: Luxembourg, 3-5 November 2010

The 10th meeting of the Washington Group on Disability Statistics (WG) was held in conjunction with the Budapest Initiative Task Force on Measuring Health Status (BI). The primary focus of the meeting was to review results obtained from the 2010 round of cognitive and field testing of the extended set of disability questions that took place in Europe (Granada Group) and South-East Asia (UN ESCAP). In collaboration with the BI, a final version of a question set on health state (a subset of the extended set on functioning) was submitted to Eurostat for inclusion on the European Health Interview Survey (EHIS). It was determined that the workgroups were ready to begin developing question sets designed to measure disability for children and environmental factors.

Eleventh meeting: Southampton, 14-16 November 2011

The Washington Group began to monitor the use of the WG Short Set in national data collections (censuses and surveys). Preliminary analyses of data provided by countries using the WG Short Set were presented. It was agreed to continue analyses of the data provided and to prepare reports for publication on the use of the WG Short Set (and other measures of disability) and the impact of wording changes to the standard set. Preliminary findings from analyses of the WG extended set of questions on functioning using data obtained from the US National Health Interview Survey (NHIS) were also presented at the meeting.

The children's workgroup presented a well-received proposal for the development of the extended set for children including a conceptual framework and examples of how the framework could be operationalized. A formal collaboration was arranged between the Washington Group and UNICEF to work on the development of the extended set of questions on child disability. The workgroup investigating environmental factors also presented their work consisting of a conceptual framework and related questions sets.

Twelfth meeting: Bangkok, 23-25 October 2012

Results from further analysis of data provided by countries using the WG Short Set in recent national data collections (censuses and surveys) were presented. It was agreed that continued analysis of the country data, focusing on a comparison of sub-populations, demographic categories and results using different cut-offs for prevalence, would be useful.

Using data from the 2011 NHIS, results from further analysis of the WG extended set of questions on functioning (ES-F) were presented. The ES-F items were examined by domain, individually, and by various socio-demographic categories. The coding choices in each domain and the cut points for definitions of disability prevalence were discussed. It was agreed that more in depth analysis would be useful and that a formal workgroup, led by the representatives from the US National Center for Health Statistics (NCHS), would be established. Delegates were encouraged to contact the WG Secretariat to join the workgroup and provide suggestions for tables to present at the 13th meeting.

The session also included a discussion on analytic guidelines and strategies for data collected using the ES-F. Representatives from NCHS provided a presentation focusing on the use of a mixed-method approach to assess validity and cross-subgroup comparability. Results from the 2010 NHIS using the ES-F questions related to pain were presented.

The workgroup investigating environmental factors and participation presented their work consisting of a conceptual framework and related questions sets. The presentation was followed by a discussion on the challenges related to developing a question set and the next steps for the workgroup. It was agreed that the workgroup should continue to move forward with the development of a question set, reducing the scope to focus on one service area or basic activity, and provide a status report of its progress at the next WG meeting.

The workgroup on the development of an extended set for measuring disability among children and youth (ES-C) presented the work accomplished in the previous year as part of its collaboration with UNICEF. Representatives from the children's workgroup provided a review of the conceptual framework for question development and a proposed set of questions. An

update on the Multiple Indicator Cluster Surveys (MICS) was presented on behalf of UNICEF, as well as, a presentation by a representative from ADAPT (formerly the Spastics Society of India) on the cognitive testing of the module on child functioning and disability in India. Following the presentations, the delegates discussed proposed question set by domain and suggested revisions were provided to workgroup. It was agreed that the workgroup will continue to collaborate with UNICEF and present the proposed final set of questions at the next meeting.

Report of the Thirteenth meeting: 29-31 October 2013 in Amman, Jordan

The 13th meeting was hosted by the Higher Council for Affairs of Persons with Disabilities (HCD) in collaboration with the Jordanian Department of Statistics. The meeting was attended by 165 persons;

- 16 representing national statistical authorities from 9 countries (Denmark, Italy-2, Jordan-7, Kenya, Mozambique, Oman, Qatar, Sudan, United Arab Emirates);
- 140 representatives from universities or national institutes of public health or other national research bodies or ministries (France, Japan, Jordan -124, Korea-2, Kuwait-2, Saudi Arabia-7, Sudan-2, United Kingdom);
- 3 representatives from the National Center for Health Statistics (WG Secretariat);
- 3 representatives from organizations representing persons with disabilities (A Global Voice for Autism (AGVFA)-2, Handicap International); and
- 3 representatives from international organizations (Pacific Islands Forum Secretariat, UNICEF, UN Women)

Objectives for the 13th WG meeting were to:

- 1) Review and approve analyses of results of country data collection using the Washington Group Short Question Set (WG SS)
- 2) Review and approve guidelines for analyzing data obtained from the Washington Group Extended Question Set on Functioning (WS ES-F)
- 3) Adopt the Extended Set of Questions on Child Disability (WG ES-C)
- 4) Review progress in developing the Washington Group Extended Set of Questions on Environmental Factors and Participation (WG ES-E/P)
- 5) Review recent international activities in disability statistics
- 6) Approve work plan

Use of the WG Short Set

The WG continues to monitor the collection of disability data internationally, and annually requests detailed information from representatives from National Statistical Offices covering survey periodicity, sample size and frame, mode of data collection, language(s) used, exact question wording along with response options and finally prevalence estimates.

The data received from 39 countries in response to the WG's request was supplemented with

information provided by countries participating in a disability seminar sponsored by the Arab Institute for Training and Research in Statistics (AITRS) in December 2010. Also, data were received from two countries (Zambia and South Africa) independent of the WG's annual request.

While countries continue to report disparate disability prevalence rates, with few exceptions, those that use the WG *as intended* (Israel [census/2008]; Aruba [census/2010]; Zambia [survey/2006]; and Maldives [survey/2009]) have reported disability prevalence rates that are comparable. Further analyses of these data are pending and a paper based on these findings will be published in 2014

WG Extended Set on Functioning

The extended set of disability questions on functioning (ES-F) were added to the US National Health Interview Survey (NHIS) beginning in 2010. During the past year, individual domain analyses were conducted on 2010 and 2011 NHIS data, and these were presented at the meeting. Analyses addressed how best to combine information from several questions per domain and develop standards for determination of cut-points. In some domains further analyses were warranted. All analyses will be compiled and presented in a document describing the properties of individual domains of functioning. The workgroup will continue to develop an analytic plan and continue analysis of the ES-F data collected on the 2011 NHIS.

Methodological Issues Concerning Surveys

The workgroup on the development of an extended set for measuring disability among children and youth (ES-C) presented the work accomplished in the previous year as part of its collaboration with the United Nations Children's Fund (UNICEF). Representatives from the children's workgroup, chaired by members from the Italian National Institute for Statistics (ISTAT), provided a review of the conceptual framework for question development and a proposed set of questions. Presentations were made of the results of cognitive testing that was completed in Oman, Belize, India, Montenegro and USA; and a revised Module on Child Functioning and Disability was presented based on these findings. The revised module will be cognitively tested in the USA prior to field testing – expected to commence early next year (2014). Plans for field testing were discussed, as well as results from some ad hoc field testing that was conducted by Italy on a pre-final version of the module. Field testing was also carried out independently by a group connected with the London School of Hygiene and Tropical Medicine in Cameroon. These results were also discussed.

The representative from UNICEF presented for review work that has begun on measuring facilitators and barriers to school participation. UNICEF also presented its work plan for the development of guidelines and accompanying documentation for the modules developed in collaboration with the WG.

Country Reports

A summary of the annual reports on national activities related to disability statistics was provided. Annual reports were completed by 48 countries. The information provided included usage of the WG Short Set of questions in the most recent round of censuses. To date, 35

countries have indicated that the short set of questions (or some variant) was included in their most recent census round. The Washington Group has also been informed that the question set has been pre-tested or added to surveys in more than 40 countries.

Individual country activities and initiatives were presented by representatives from Argentina, Oman, Italy, and the Pacific Islands Forum Secretariat. These covered, respectively, results of the 2010 national population census, cognitive and field testing of the child disability module and issues of regional importance to disability measurement and rights.

New initiatives

The development of measures specific to mental health was presented to the Meeting for discussion – and a proposal made for the creation of a workgroup to address this task. A call was made for individuals interested in leading or participating in this workgroup to contact the WG Secretariat.

The WG will also, at the request of members, look into the use of data registers in the compilation of disability statistics.

Key agreements of the 13th meeting and next steps:

The WG agreed to its work plan for 2014. 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 steering committee and workgroups include:

- 1) Work on the short set questions (WG SS):
 - a) Finalize a paper for publication reporting on the use of the WG SS – and other measures of disability – and the impact on the data obtained of wording changes to the standard set.
 - b) Present the final up-date of analyses of results of country data collection using the WG SS and presentation of the published paper at the 14th meeting.
- 2) Work on the extended sets of questions on functioning (WG ES-F):
 - a) Continue analyses of data from the US NHIS.
 - b) Prepare a paper for publication on analysis of the NHIS data.
 - c) Review and approve guidelines for analyzing data obtained from the WG ES-F.
 - d) Present guidelines for analysis at the 14th meeting.
- 3) Work on extended sets of questions on child disability (WG ES-C):
 - a) Continue development of the module on child functioning and disability through field testing of the module.
 - b) Present results from analyses of field testing at the 14th meeting.
 - c) Collaborate with UNICEF on the development of a manual for implementation of the WG ES-C.
 - d) Present a draft of manual for implementation of the WG ES-C at the 14th meeting.

- e) Prepare documents on the development of measures of child disability for presentation at the 14th meeting.
- 4) Work on extended sets of questions on environmental factors and participation:
 - a) Continue work on the development of the conceptual framework and develop a proposed set (or sets) of questions.
 - b) Review progress in development of measures of facilitators and barriers to school participation for children.
 - c) Present a draft survey module at the 14th meeting.

Objectives for the 14th WG meeting:

- To present the final up-date of analyses of results of country data collection using the Washington Group Short Question Set (WG SS) and presentation of the published paper
- To review and approve guidelines for analyzing data obtained from the Washington Group Extended Question Set on Functioning (WG ES-F)
- To present additional work on the Extended Set of Questions on Child Disability (WG ES-C)
 - 1) Present results from analysis of field test data
 - 2) Present manual for implementation of WG ES-C
 - 3) Adopt final question module
- To review progress in development of measures of facilitators and barriers to school participation for children
- Newly formed workgroups to present on progress of new WG initiatives (if any)
- To review recent international activities in disability statistics

Governance issues

The 14th WG meeting is scheduled to be held October 8-10, 2014 in Buenos Aires, Argentina.

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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