

Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 14th 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 to be used as components of population surveys or as supplements to specialty surveys. To that end, the WG has developed, tested and adopted an extended set of questions on functioning; and, in collaboration with UNICEF, is working on survey modules that address child functioning and disability as well as inclusive education. 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 14 meetings.

There are currently representatives from national statistical authorities in 130 countries and territories: Afghanistan, Albania, Argentina, Armenia, Aruba, Australia, Austria, Azerbaijan, 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, Colombia, Costa Rica, Croatia, Cuba, Curacao, Cyprus, Czech Republic, Democratic Republic of the Congo, Denmark, Dominican Republic, Egypt, Estonia, Fiji, Finland, France, Gambia, Georgia, Germany, Ghana, Greece, Guatemala, Hungary, India, Indonesia, Iran, Iraq, Ireland, Israel, Italy, Ivory Coast, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Korea, Kuwait, Kyrgyz Republic, Lao, Latvia, Lebanon, Lesotho, Lithuania, Luxembourg, Malawi, Maldives, Malta, Mauritius, Mexico, Micronesia, Moldova, Mongolia, Monserrat, Morocco, Mozambique, the Netherlands, New Zealand, Norway, Oman, Pakistan, Palestine, Panama, Papua New Guinea, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Romania, Rwanda, Saint Lucia, Saint Maarten, Samoa, Saudi Arabia, Serbia and Montenegro, Sierra Leone, Singapore, the Slovak

Republic, Slovenia, Somalia, South Africa, Spain, Sri Lanka, Sudan, Sweden, Syria, Tanzania, Thailand, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkey, Tuvalu, Uganda, United Arab Emirates, United Kingdom of Great Britain and Northern Ireland, United States of America, Uruguay, Vanuatu, Venezuela, Viet Nam, Yemen, Zambia, and Zimbabwe. In the past, Antigua and Barbuda, the Bahamas, Comoros, Ecuador, Nigeria, and the Turks and Caicos Islands have also participated.

Past and present representatives of international organizations representing persons with disabilities (DPO) include the European Disability Forum, Handicap International, Rehabilitation International, the Inter-American Institute on Disability, the African Rehabilitation Institute, the International Federation for Spina Bifida and Hydrocephalus and the International Disability Alliance (IDA). 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 Higher Council for Affairs of Persons with Disabilities (HCD).

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 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 specific question modules designed to measure disability among children. 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. Using data from the 2011 NHIS, results from further analysis of the WG extended set of questions on functioning (ES-F) were presented. 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 workgroup (in collaboration with UNICEF) on the development of specific question modules designed to measure disability among children presented 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.

Thirteenth meeting: Amman, 29-31 October 2013

Results from the continued analysis of data provided by countries using the WG Short Set in recent national data collections (censuses and surveys) were presented. While countries continue to report disparate disability prevalence rates, with few exceptions, those that use the WG Short Set questions *as intended* have reported disability prevalence rates that are comparable. Further analyses of these data and a paper based on these findings are part of the work plan for 2014.

Using data from the 2010 and 2011 NHIS, results from further analysis of the WG extended set of questions on functioning (ES-F) were presented. Analyses addressed how best to combine information from several questions per domain and develop standards for determination of cut-points.

The workgroup on the development of specific question modules designed to measure disability among children 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. 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 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. The workgroup was encouraged to continue its collaboration with UNICEF to development of the module on child functioning and disability

There was a presentation on whether and how issues related to mental health could be incorporated into the work of the WG. A proposal was made to create a workgroup to further address this issue and a call was sent to WG members to identify individuals interested in leading or participating in this workgroup. Interest was expressed in having the WG look into the use of data registers in the compilation of disability statistics. A call was made to see if there is interest in setting up a workgroup on this topic.

Report of the Fourteenth meeting: 8-10 October 2015 in Buenos Aires, Argentina

The 14th meeting was hosted by the National Institute of Statistics and Censuses (INDEC). The meeting was attended by 103 persons;

- 53 representing national statistical authorities from 14 countries (Argentina-38, Canada-2, China – Hong Kong SAR, Colombia, Costa Rica, Denmark, Egypt, Italy-2, Mexico, Panama, St. Maarten, Samoa, Spain, Tunisia);
- 43 representatives from universities or national institutes of public health or other national research bodies or ministries (Argentina-34, Australia, China, Japan, Saudi Arabia-3, South Africa-2, United Kingdom);
- 4 representatives from the US National Center for Health Statistics (WG Secretariat);
- 1 representative from an organization representing persons with disabilities (Handicap International); and
- 2 representatives from international organizations (Eurostat, UNFPA)

Objectives for the 14th WG meeting were to:

- Present a final update of analyses of results of country data collection using the WG Short Question Set (WG SS)
- Review and approve guidelines for analyzing data obtained from the WG Extended Question Set on Functioning (WG ES-F)
- Present additional work on the UNICEF/WG Module on Child Functioning and Disability
- Review progress in the development of module on inclusive education
- Review progress of new WG initiatives
- Review recent international activities in disability statistics

- 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 prevalence estimates.

Data were received from 51 countries: Twenty-six countries reported census results and 25 countries reported survey results. Some countries reported census or survey data that pre-date the 2006 adoption of the WG short set of questions; and there was a clear distinction between countries that took a more medical-model approach to identifying disability on their census or survey (i.e. by listing impairments or types of disability) and those that operationalized a social-model approach (by addressing activity limitations).

Although countries have reported disparate disability prevalence rates; with few exceptions, those that use the WG as intended, using a cut-off of least one domain that is coded as a lot of difficulty or cannot do it at all, have reported disability prevalence rates that are comparable – in the range 7 – 10%. Further analyses of these data are pending and a paper based on these findings will be published in 2015.

The following milestones were presented with respect to the further endorsement of the WG short set of questions:

- A UN Expert Meeting convened in Paris in July 2014 endorsed the WG questions as a means for disaggregating disability data for the post-2015 Sustainable Development Goals.
- DFID (Department for International Development/UK) has recommended the WG short set for all programs and projects that include disability as a measurement or demographic.
- DFAT (Australian Government Department of Foreign Affairs and Trade) is working with the WG to build capacity to implement the questions in censuses and surveys and to facilitate the analysis and dissemination of the resulting data.
- UNSD and UN Economic Commission for Europe (ECE)/Conference of European Statisticians (CES) have recommended the WG short set of questions for the 2020 round of censuses.
- United States Agency for International Development (USAID) will prepare a disability module for their Demographic and Health Surveys that will include the WG short set of questions.

A representative from the hosting organization, INDEC, provided a presentation on results from the 2010 National Population Census in Argentina. Questions similar to the WG short set of questions were included on the Census. The representative from INDEC explained that the modifications were made to the WG questions based on results for the pilot test and to remain consistent with the structure used in other national data collections. Prevalence rates for disability were presented by age categories, sex, region, education, occupation, and health insurance coverage. Using the modified questions, the 2010 Census yielded a total population prevalence rate for disability of 12.9%.

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, analyses of individual domains were finalized using 2010 and 2011 NHIS data. Algorithms for combining multiple domain questions into single domain indicators of disability and developing standards for determination of cut-points were presented. The presentation was followed by a discussion of the proposed algorithms and cut-points for each domain. The delegates agreed on the completed domains and identified certain domains that required some slight modifications or further analysis. A small workgroup will finalize the analysis for the outstanding domains. All analyses will be compiled and presented in a document describing the properties of individual domains of functioning.

Methodological Issues

The workgroup on the development of specific question modules designed to measure disability among children presented the work accomplished in the previous year as part of its collaboration with the United Nations Children's Fund (UNICEF). Presentations were provided on the development of the module including past and recent developments; the results of the cognitive testing carried out in Oman, Belize, India, Montenegro and the USA – with a presentation of a revised version of the Module on Child Functioning and Disability based on the cognitive testing results. The revised module will be field tested in 2015. A representative from the London School of Hygiene and Tropical Medicine presented results using a pre-final version of the module in Cameroon and India. Results using a pre-final version of the module in South Africa were presented by a representative from the University of the Free State.

Recent work on measuring facilitators and barriers to school participation was also presented and a survey module on inclusive education will be developed in 2015 for cognitive and field testing. Preliminary results are anticipated for the 2015 meeting of the WG in October.

The workgroup investigating the development of measures specific to mental health, currently led by the representative from South Africa, presented the work accomplished in the previous year. The presentation included a review of a background document that has been drafted describing the global impact of mental health disorders; providing a brief review of the measures that are commonly used; and citing some examples of countries that collected data on mental health. The presentation was followed by a discussion of the next steps for the workgroup. The delegates agreed that the workgroup should continue its review of existing measures before attempting to develop new measures. The workgroup will provide an update on its status at the next WG meeting. The workgroup has been operating with contributions from a small number of members and the representative from South Africa serving as the interim chair. At the conclusion of the session, a call was made for the participation of additional members and a volunteer to chair the workgroup. Individuals were asked to contact the WG Secretariat if interested in leading or participating in this workgroup.

Following the thirteenth meeting, a call was sent to the WG membership to see if there was interest in setting up a workgroup to explore the use of data registers in the compilation of disability statistics. A representative from the Aruba Central Bureau of Statistics expressed interest in this

topic. He agreed to explore the feasibility of this initiative and provide a progress report at the fourteenth meeting. The chair of steering committee provided an update of the work accomplished over the past year on behalf of the representative from Aruba. The presentation included a literature review of publications containing information of disability registers, an inventory data sources (existing and potential), and general recommendations for next steps. At the conclusion of the presentation, the delegates indicated that they would like to see the workgroup continue its efforts and provide a status update at next year's meeting.

Two representatives from the Saudi Disability Registry Group (SDRG) presented on their experience in attempt to develop a national disability registry in Saudi Arabia. The presentation included a discussion of the need for a national database containing information on disability in Saudi Arabia, some of the challenges that have been encountered in their efforts, and an outline of the roadmap for development of the registry. Following the presentation, the Saudi representatives were commended for their efforts by the delegates and received encouragement to continue their work.

Following the presentation from the SDRG, a short video was shown that highlighted their work. The video is available here: <https://vimeo.com/108280891> (password: sndr)

Country Activities

A summary of the annual reports on national activities related to disability statistics was provided. Annual reports were completed by 44 countries. The information provided included usage of the WG Short Set of questions in the most recent round of censuses. To date, 38 countries have indicated that the short set of questions (or some variant) was included in their most recent census round. The WG has also been informed that the question set has been pre-tested or added to surveys in 50 countries.

Individual country activities were presented by representatives from Argentina and Colombia. These covered, respectively, results from the pilot test for the Second National Survey of Persons with Disabilities in Argentina and cognitive testing of disability questions in preparation for the National Housing and Population Census in Colombia.

Following the presentations on country activities, the chair of the WG steering committee led a discussion on developing strategies for analysis, implementation, and dissemination of data collected using the WG questions. It was agreed that providing countries with guidance on implementation of the WG questions and dissemination of the data collected should become areas of focus for the WG and a new workgroup was formed to address these tasks. The WG Secretariat (NCHS) will serve as the interim chair and the workgroup will report on any developments at the next meeting.

Key agreements of the 14th meeting and next steps:

The WG agreed to its work plan for 2015. 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) and extended sets of questions on functioning (WG ES-F):
 - 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) Finalize analyses of WG ES-F data from the US NHIS
 - c) Finalize guidelines for analyzing data obtained from the WG ES-F
 - d) Focus on development of strategies for implementation and dissemination of data collected using the WG questions

- 2) Work on the UNICEF/WG Module on Child Functioning and Disability:
 - a) Continue field testing and use test results to inform additional changes
 - b) Continue collaboration with UNICEF to finalize a manual for implementation of the module
 - c) Present a final version of the module and manual for implementation at the 15th meeting

- 3) Work on module measuring inclusive education:
 - a) Continue collaboration with UNICEF on the development of the module including cognitive and field testing
 - b) Continue collaboration with UNICEF on the development of a manual for implementation
 - c) Present a draft version of the survey module and manual for implementation at the 15th meeting

- 4) Work on other methodological areas:
 - a) Continue work on development of measures specific to mental health
 - b) Continue work related to the use of data registers in the compilation of disability statistics
 - c) Revisit work on the development of extended sets of questions on environmental factors and participation

Objectives for the 15th WG meeting:

- To present any updates to analyses of WG Short Question Set (WG SS) and Extended Question Set on Functioning (WG ES-F)
 - Present results from combined domain analysis using WG ES-F
 - Present guidelines for analyzing data obtained from the WG ES-F
- To present additional work on the UNICEF/WG Module on Child Functioning and Disability
 - Present results from analysis of field test data
 - Present manual for implementation of the module
 - Adopt final question module
- To review progress in development of the module on inclusive education
 - Present draft module
 - Present results from analysis of cognitive and field test data and proposed revisions based on the tests

- Present progress in work on measures specific to mental health
- Present progress in work on the use of data registers in the compilation of disability statistics
- Review progress in developing the WG Extended Set of Questions on Environmental Factors and Participation (WG ES-E/P):
 - Review proposed questions
- Review recent international activities in disability statistics
- Approve work plan

Governance issues

The 15th WG meeting is scheduled to be held October 27-29, 2015 in Copenhagen, Denmark.

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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