Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 12th 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 12 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, 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.

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. Methodological issues that were raised earlier concerning the development of questions for children and institutionalized populations were revisited. 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).

Issues of methodology with respect to special populations such as children with disabilities were revisited. A presentation on the development of a cross-culturally useful extended set of questions to measure environmental factors was also given. Based on the presentations at the 10th meeting, 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 at the 11th meeting. Of particular interest was the impact of modifications that had been made by certain countries to the question set. 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 disability questions using data obtained from the US National Health Interview Survey (NHIS) were also presented at the meeting. The discussion focused on how the data could be used to better understand the question set and to provide analytic guidance. Results from further analyses were to be presented at the 12th WG meeting.

Two workgroups -- on the development of an extended set for measuring disability among children and youth, and for measuring the environment as it relates to functioning – presented the work accomplished in the previous year. 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. In addition, a session was held on how participation could be addressed more directly. The environmental factors workgroup was encouraged to continue work in both these areas and present an update at the next meeting.

Report of the Twelfth meeting: 23-25 October 2013 in Bangkok, Thailand

The 12th meeting was hosted by the Statistics Division of the United Nations Economic Commission for Asia and the Pacific (ESCAP). The meeting was attended by 40 persons;

• 20 representing national statistical authorities from 18 countries (Albania, Australia, Bermuda, Botswana, Cambodia, Denmark, Israel, Italy-2, Maldives, Mongolia, Norway,

Oman, Philippines-2, Sint Maarten, Sri Lanka, Sweden, Thailand, and United Arab Emirates);

- 7 representatives from universities or national institutes of public health or other national research bodies or ministries (China, France, Ireland, Japan, Jordan-2 and South Africa);
- 3 representatives from the National Center for Health Statistics (WG Secretariat);
- 3 representatives from organizations representing persons with disabilities (ADAPT (formerly The Spastics Society of India)-2 and the International Disability Alliance (IDA)); and
- 7 representatives from international organizations (European Union Agency for Fundamental Rights (FRA), UN ESCAP-5, and the World Health Organization (WHO))

Objectives for the 12th WG meeting were to:

- 1) Present additional work on short set questions:
 - a. results from further analysis of country reports using WG short set questions in surveys / censuses
- 2) Present additional work on extended set on functioning:
 - a. results from further analyses of data from the US National Health Interview Survey (NHIS)
- 3) Present additional work on the development of questions on child functioning and disability:
 - a. presentation of proposed question set
- 4) Present additional work on extended sets of questions on environmental factors and participation:
 - a. conceptual framework and feasibility of developing a proposed set (or sets) of questions measuring environmental factors and participation
- 5) Discuss strategic issues.

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, the actual questions operationalized with response options and finally prevalence data. At the 11th meeting in Southampton, preliminary results of analyses of the country data were presented. Results from further analysis of the country data were presented at the meeting the 12th meeting in Bangkok.

In all, 34 countries were represented in the analysis. The data received from 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 was received from two countries (Zambia and South Africa) independent of the WG's annual request.

We have found that while countries have reported 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: 6.4%, 6.9%, 8.5%, and 9.6% respectively. Again it can be noted that prevalence results generated from surveys generally produce higher rates than those generated from a census. This is in part due to the fact that surveys provide a different context for the questions than does a Census and are unrestricted in the number of questions that can be included.

The delegates 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. It was also agreed that an analysis of data provided for children collected using the WG-SS could be used to inform the development of the Module of Child Disability and Functioning. A paper is currently being prepared for publication that reports on the use of the WG SS (and other measures of disability) and the impact of wording changes to the standard set using the data collected internationally. Results from the additional analyses would be presented at the 13th meeting.

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. Preliminary findings from analysis of the 2010 NHIS data were presented at the 11th meeting. Results from further analysis of the WG ES-F using data from the 2011 NHIS were presented at the 12th meeting. 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. The delegates 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. The workgroup will develop an analytic plan and continue analysis of the ES-F data collected on the 2011 NHIS. 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.

Methodological Issues Concerning Surveys

The workgroup investigating environmental factors and participation, chaired by the US National Center for Health Statistics, 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. The delegates 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. The workgroup will 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 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. 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. The delegates agreed that the workgroup will continue to collaborate with UNICEF and present the proposed final set of questions at the next meeting.

Country Reports

A summary of the annual reports on national activities related to disability statistics was provided. Annual reports were completed by 42 countries. The information provided included usage of the WG Short Set of questions in the most recent round of censuses. The primary representatives from 11 countries indicated that the short set of questions 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 30 countries.

The WG representatives from Botswana, Maldives, and Sri Lanka provided presentations on their countries' experiences collecting disability data. The representative from Botswana provided a brief presentation focusing on the government's role in improving the collection of data on disability. The representative from Maldives provided a brief overview of the 2009 Maldives Demographic Health Survey (MDHS) and presented preliminary results from analysis of data collected using the WG SS questions. The representative from Sri Lanka provided a brief presentation on her experiences during the pilot testing of the WG ES-F.

Updates on other Washington Group and collaborative activities

A representative from UN ESCAP's Social Development Division provided an overview of the Incheon Strategy, a framework designed to guide action on disability in the Asian-Pacific region over the next decade. The Incheon Strategy is based on the principles of the UN Convention on the Rights of Persons with Disabilities and includes the following goals:

- Reduce poverty and enhance work and employment prospects
- Promote participation in political processes and decision-making

- Enhance access to the physical environment, public transportation, knowledge, information and communication
- Strengthen social protection
- Expand early intervention and education of children with disabilities
- Ensure gender equality and women's empowerment
- Ensure disability-inclusive disaster risk reduction
- Improve the reliability and comparability of disability data
- Accelerate the ratification and implementation of the Convention on the Rights of Persons with Disabilities and harmonization of national legislation with the Convention
- Advance sub-regional, regional and interregional cooperation

The Incheon Strategy is scheduled to be officially launched at the UN ESCAP High-level Intergovernmental Meeting on the Final Review of the Implementation of the Asian and Pacific Decade of Disabled Persons (2003-2012) on October 29 through November 2, 2012 in Incheon, Korea.

A representative from the World Health Organization (WHO) provided an overview of the World Report on Disability, launched in June 2011, and the Model Disability Survey scheduled to be launched in 2013. Both projects were joint collaborations between WHO and the World Bank. The World Report was a resulted from a World Health Assembly resolution aimed to:

- provide governments and civil society with a comprehensive analysis of the importance of disability and the responses provided, based on best available evidence
- recommend national and international action to improve the lives of persons with disabilities
- support implementation of the Convention on the Rights of Persons with Disabilities

Over 380 people from 70 different countries contributed to the report, including academics, policy-makers, professionals, disability rights advocates and non-governmental organizations. Several recommendations were made in the World Report including:

- Enable access to all mainstream policies, systems and services
- Invest in specific programmes and services for persons with disabilities
- Adopt a national disability strategy and plan of action
- Involve people with disabilities
- Improve human resource capacity
- Provide adequate funding and improve affordability
- · Increase public awareness and understanding of disability
- Improve disability data collection
- Strengthen and support research on disability

To support the implementation of recommendations of the World Report on Disability, WHO and the World Bank began working on the development of the Model Disability Survey. An overview of the question development process and the timeline for implementation were presented. The final question set is expected to be released by the end of 2013.

Key agreements of the 12th meeting and next steps:

The WG agreed to its work plan for 2013. 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) Continue analysis of data provided by countries.
 - b) Prepare a paper for publication reporting on the use of the Washington Group Short Set of questions (and other measures of disability) and the impact of wording changes to the standard set on the data obtained.
 - c) Prepare a presentation on the analysis for the 13th meeting.
- 2) Work on the extended sets of questions on functioning (ES-F):
 - a) Workgroup established to analyze data from the US NHIS.
 - b) Prepare a paper for publication on analysis of the NHIS data.
 - c) Prepare a presentation on the analysis for the 13th meeting.
- 3) Work on extended sets of questions on child disability (ES-C):
 - a) Make revisions based on suggestions provided by meeting participants
 - b) Continue cognitive and field testing and use test results to inform additional changes
 - c) Continue collaboration with UNICEF
 - d) Present proposed final set of questions at the 13th meeting
- 4) Work on extended sets of questions on environmental factors and participation (ES-E/P):
 - a) Continue work on the development of a proposed set (or sets) of questions.
 - b) Reduce the scope and focus on one service area or basic activity
 - c) Present additional work on proposed question set at the 13th meeting.

Objectives for the 13th WG meeting:

- Review and approve analyses of results of country data collection using the Washington Group Short Question Set (WG SS):
 - presentation of further analysis of country reports of data obtained from surveys and Censuses
- Review and approve guidelines for analyzing data obtained from the Washington Group Expended Question Set on Functioning (WS ES-F):
 - presentation of analyses of data from the US National Health Interview Survey (NHIS)
- Adopt the Extended Set of Questions on Child Disability (WG ES-C):
 - present results of cognitive and fields tests of the WG ES-G and proposed revisions based on the tests
- Review progress in developing the Washington Group 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 13th WG meeting is tentatively scheduled to be held October 29-31, 2013 in Amman, Jordan.

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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