

## **Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 11<sup>th</sup> Annual Meeting**

### **Purpose**

The main purpose of the Washington Group is the promotion and co-ordination of international co-operation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability which is comparable throughout the world. More specifically, the Washington Group set a goal of developing a short set of 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. 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 the sets. All disability measures recommended by the group, short or extended, are accompanied by descriptions of their technical properties, and methodological guidance is given on their implementation and their applicability to all population subgroups. The Washington Group 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 11 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, Saint 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, and Bermuda Hospitals Board.

Other international organizations that have previously participated or currently participate in the Washington Group include EUROSTAT, Partnership Health EU, the International Labor Organization, the Organization for Economic Cooperation and Development, the Inter-American Development Bank, the International Development Project, the World Bank, the World Health Organization, World Health Organization Family of International Classifications Collaborating Center, the United Nations 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 6<sup>th</sup> meeting. A large part of the 7<sup>th</sup> 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 UNESCAP.

*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 UNESCAP. Methodological issues were raised during the 8<sup>th</sup> 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 9<sup>th</sup> 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 9<sup>th</sup> 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 UNESCAP 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 UNESCAP in the Asia and Pacific region, also be established in other regions.

*Tenth meeting: Luxembourg, 3-5 November 2010*

The 10<sup>th</sup> 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 (UNESCAP). 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 10<sup>th</sup> meeting, it was determined that the workgroups were ready to begin developing question sets designed to measure disability for children and environmental factors.

### **Report of the Eleventh meeting: 14-16 November 2011 in Southampton, Bermuda**

The 11<sup>th</sup> meeting was hosted by the Bermuda Government, Department of Statistics. The meeting was attended by 42 persons;

- 16 representing national statistical authorities from 10 countries (Argentina, Barbados, Bermuda-7, China (Hong Kong SAR), Israel, Italy, Mexico, Oman, Peru, and Sweden);
- 18 representatives from universities or national institutes of public health or other national research bodies or ministries (Antigua, Bermuda-13, France, Ireland, Japan, and South Africa);
- 5 representatives from the National Center for Health Statistics (WG Secretariat);
- 1 representative from international organizations (UNICEF);
- 2 Distinguished Alumni

Objectives for the 11<sup>th</sup> WG meeting were to:

- 1) Present results of country reports using WG short set questions in surveys / censuses
- 2) Present additional work on extended sets:
  - a. results from further analyses of cognitive and field testing data
  - b. update on expansion of cognitive and field testing of the extended set of questions to other regions and presentation of results (if any)
  - c. update on any revisions to extended set questions
- 3) Present status reports from the workgroups on measurement of child disability and environmental factors
- 4) Discuss strategic issues.

### Use of the WG Short Set

The Washington Group is monitoring the use of the short set in the 2010 round of Censuses. Information on questions used and resulting estimates of disability was requested from the Washington Group. Preliminary analyses of the country results were presented at the 11<sup>th</sup> meeting. Of particular interest was the impact of modifications that had been made by certain countries to the question set and/or the response categories. Discussion focused on how these findings could be used to better inform countries about the collection of disability information

and the potential impact of question wording. Delegates agreed that a paper that provided summary information on the results received to date and an analysis of the effects of question wording would be beneficial to countries. This project was adopted as part of the 2012 work plan.

A representative from the Israel Central Bureau of Statistics (CBS) presented on persons with disabilities and community life in Israel. The analysis used data from Israel's 2010 Social Survey which included the WG short set questions for 5 domains (vision, hearing, mobility, self-care, and cognition).

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using hearing aid?
3. Do you have difficulty walking or climbing stairs?
4. Do you have difficulty in getting dressed or washing?
5. Do you have difficulty remembering or concentrating?

Response options were: No, no difficulty, Yes, some difficulty, Yes, a lot of difficulty, and Cannot do at all.

Overall using this approach, and with a disability cutoff of a lot of difficulty or cannot do at all, they found that 15% of the total population aged 20 and more is defined as disabled. Results were presented by background socio-demographic factors.

A representative from the National Institute of Statistics and Census in Argentina provided a presentation on the measurement of disability in Argentina. Questions similar to the WG short set of questions were included on 2010 National Population Census.

Translated, the following questions were included on the 2010 Census:

Do you have difficulty or a permanent limitation in:

1. Seeing, even with glasses or lenses?
2. Hearing, even when you use a hearing aid?
3. Walking or climbing steps?
4. Grabbing objects and/or opening containers with your hands?
5. Understanding and/or learning?

Response categories were Yes/No.

Previously, the 2001 Census yielded a population prevalence rate for disability of 8.3% and the 2002-2003 National Survey of People with Disabilities (ENDI) yielded a population prevalence rate of 7.1%. Using these questions, based on the WG, the prevalence rate was 13.0%.

The WG representative from Oman provided a presentation on Oman's experience collecting disability data in three national censuses (1993, 2003, and 2010).

The representative from Oman indicated that the new methodology adopted by the 2010 census for collecting data on disability, which was based on the recommendations of the Washington Group for Disability Statistics, gave more reliable data than previously. This was reflected in the increased prevalence rate of 3.2%, compared to 2.3% as observed in the 2003 Omani Census. The representative concluded that this rate, although less than the international rate which ranged

between 50-80 per thousand population, was an improvement over the previous index and close to the international index.

The results of these three presentations (Israel, Argentina, and Oman) also feed into the recommendation above, that question wording and response options play an important role in understanding the results achieved – and in, finally, meeting international expectations.

#### WG Extended Set on Functioning

The extended set of disability questions on functioning were added to the 2010 US National Health Interview Survey (NHIS). Preliminary findings were presented at the 11<sup>th</sup> meeting. Much of the discussion focused on how the data could be used to better understand the question set and to provide analytic guidance. Delegates agreed that more in depth analysis would be useful. The US National Center for Health Statistics, along with interested Washington Group members, will continue analysis of data from the US NHIS. It was also agreed that a paper would be prepared for publication on analysis of the NHIS data.

#### Update on the expansion of cognitive and field testing in the Middle East region

In 2010 and 2011, representatives from the WG Secretariat have participated in several training workshops in the Middle East region. An update was provided on the recent training activities that have taken place. A training workshop for question evaluation and cognitive interview methodologies was held in Muscat, Oman in October 2010. The objectives were to inform researchers of, and train them in, current cognitive interview methodology and question evaluation techniques with respect to the Washington Group extended set of disability questions. The workshop was hosted by the Ministry of National Economy and was attended by 15 representatives from NSOs of 9 Arab countries (Syria, Jordan, Tunisia, Sudan, Oman, Palestine, Egypt, Yemen & Morocco).

In December 2010, the Arab Institute for Training and Research in Statistics (AITRS) sponsored a disability seminar in Damascus, Syria. The specific goals were to transfer knowledge with representatives from NSOs from Arab countries on disability definition and measurement. The seminar was attended by 22 representatives from NSOs from 12 Arab countries (Syria, Jordan, Bahrain, Tunisia, Sudan, Iraq, Oman, Palestine, Libya, Egypt, Morocco and Yemen).

In May 2011, representatives from the Secretariat participated in a training workshop in Sharjah, United Arab Emirates (UAE) sponsored by AITRS. The aim was to train representatives from NSOs from Arab countries in understanding and operationalizing disability measures developed by the Washington Group. The training workshop was attended by 35 representatives from NSOs of 15 Arab countries (Jordan, UAE, Bahrain, Tunisia, Djibouti, Saudi Arabia, Sudan, Syria, Somalia, Iraq, Oman, Kuwait, Lebanon, Egypt, and Morocco), and the UN Relief and Works Agency (UNRWA).

### Methodological Issues Concerning Surveys

Two work groups -- 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 work group, chaired by members from the Italian National Institute for Statistics (ISTAT), 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 delegate from UNICEF attended the meeting and presented information on the survey items used in the Multiple Indicator Cluster Surveys (MICS). 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 work group investigating environmental factors, chaired by the US National Center for Health Statistics, 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 work group was encouraged to continue work in both these areas.

### Country Reports

A summary of the annual reports on national activities related to disability statistics was provided. Annual reports were completed by 38 countries. The information provided included usage of the WG Short Set of questions in the most recent round of censuses. The primary representatives from 10 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.

### Updates on other Washington Group and collaborative activities

The final version of the Budapest Initiative’s (Task Force on the Measurement of Health Status, also known as BI) question set on health state was adopted in November 2010 at the joint Washington Group-BI meeting in Luxembourg and subsequently presented to Eurostat (as part of the Budapest Initiative) for inclusion in the next round of the European Health Interview Survey (EHIS).

In February 2011, an expert group meeting was held in Bangkok to review the results of a second round of cognitive testing of the Washington Group/UNESCAP extended question set to measure disability through surveys. The objectives were to discuss the results of the second round of cognitive testing of the question set on disability, in particular on the domains of communication, hearing, affect, pain and fatigue; further train senior statisticians from Asia-Pacific on the skills required to undertake the analysis of cognitive interviews; and discuss future areas of work on disability data collection and measurement. Discussions have continued with the UNESCAP to explore the development of an implementation project.

The Washington Group continues to seek the support of the World Bank in continuing the development of disability measures. Discussions continue with the World Bank in matters of

common interest and in attempts to secure funding for further activities in the testing and development of extended sets of questions on disability in other regions. Discussions have taken place with the UN Department of Social and Economic Affairs regarding the use of the Washington Group questions for the purpose of monitoring the UN Convention on the Rights of Persons with Disability. New contacts have been established in the Middle-East with the Arab Institute for Training and Research in Statistics (AITRS).

A more formal collaboration was arranged between the Washington Group and the United Nations Children's Fund (UNICEF) in the development of the extended sets of disability questions on child disability.

In June 2011 the World Report on Disability was launched by the WHO and the World Bank. In order to enhance the availability, comparability and quality of data on disability the World Report proposes several recommendations that reflect directly on the work of the Washington Group:

- That improved national disability statistics through the routine collection of disability data become incorporated into national statistics programs.
- The development of appropriate tools (quantitative and qualitative methodologies) to improve and expand data collection on disability.
- The collection of national population census data according to the recommendations from the Washington Group on Disability Statistics and the UN Statistical Commission.
- That the questions developed by the Washington Group and Budapest Initiative provide a core set that can be expanded to meet country needs.
- The development and testing of extended measures of disability for use in population surveys or as the core of a disability survey as initiated by the Washington Group and Budapest Initiative.
- That NSOs be encouraged to actively participate in the Washington Group as a means of improving data quality, comparability, and availability.

A representative of the Washington Group participated in the world release of the Report at the UN in New York (June, 2011) and the US release in Washington DC (September, 2011). The Washington Group is committed to addressing the recommendations of the Report.

#### Key agreements of the 11<sup>th</sup> meeting and next steps:

The WG agreed to its work plan for 2012. 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:
  - a) 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.

- b) Prepare a presentation on the analysis for the 12<sup>th</sup> meeting.
- 2) Work on the extended sets of questions on functioning (ES-F):
  - a) Interested Washington Group members will continue analyses of data from the US NHIS and prepare a paper for publication on analysis of the NHIS data.
  - b) Prepare a presentation on the analysis for the 12<sup>th</sup> meeting.
- 3) Work on extended sets of questions on child disability (ES-C):
  - a) The work group on child disability will continue to develop their proposal on the question set for children and develop a proposed question set.
  - b) The work group will collaborate with UNICEF on the development of the extended set of child disability measures; and
  - c) Prepare documents on the development of measures of child disability for the twelfth meeting.
- 4) Work on extended sets of questions on environmental factors and participation (ES-E/P):
  - a) Continue work on the development of the conceptual framework and the feasibility of developing a proposed set (or sets) of questions.
  - b) Prepare documents on the development of measures of environmental factors and participation for the 12th meeting.

Objectives for the 12<sup>th</sup> WG meeting:

- Present additional work on short set questions:
  - results from further analysis of data collected during the 2010 round of Censuses
- Present additional work on extended set on functioning:
  - results from further analysis of data from the US NHIS
- Present additional work on extended sets of questions on child disability:
  - proposed question set of child disability measures
- Present additional work on extended sets of questions on environmental factors and participation:
  - proposed set (or sets) of questions measuring environmental factors and participation
- Discuss strategic issues.

Governance issues

The 12<sup>th</sup> WG meeting is tentatively scheduled to be held October 2012 in Beijing, China.

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](http://www.cdc.gov/nchs/washington_group.htm)).

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