

Report of the Washington Group (WG) on Disability Statistics

Purpose:

The main purpose of the WG is the promotion and co-ordination of international co-operation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys which will provide basic necessary information on disability throughout the world. More specifically, the WG aims to guide the development of a short set(s) 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. The second priority of the Washington Group 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(s) of disability measures. The WHO International Classification of Functioning, Disability and Health (ICF) have been accepted as the basic framework for the development of the sets. All disability measures recommended by the group, short or extended will be accompanied by descriptions of their technical properties, and methodological guidance will be given on their implementation and their applicability to all sections of the population. The WG will disseminate work products globally through the world-wide web.

Year organized: 2001

Participants:

Representatives of national statistical offices, international organizations, and non-government organizations have participated in the last 5 meetings.

Current country representatives include (from national statistical offices): Argentina, Australia, Austria, Bahamas, Belgium, Brazil, Canada, Costa Rica, Czech Republic, Democratic Republic of Congo, Denmark, Ecuador, Egypt, Finland, France, Greece, Guatemala, Hong Kong Special Administrative Region of China, India, Ireland, Israel, Italy, Kenya, Latvia, Lesotho, Macao Special Administrative Region of China, Malawi, Mauritius, Mexico, New Zealand, Norway, Occupied Palestinian Territory, Panama, Paraguay, Peru, Philippines, Poland, Romania, Sierra Leone, Slovenia, South Africa, Spain, Saint Lucia, Sweden, The Netherlands, Turkey, Turks and Caicos Islands, Uganda, United Kingdom of Great Britain and Northern Ireland, United States of America, and Viet Nam.

Current non-government organizations include: European Disability Forum, EUROSTAT, Inter-American Institute on Disability, International Labor Organization, Organization for Economic Cooperation and Development, National Disability Authority, Ireland, Partnership Health EU, Inter-American Development Bank, International Development Project, World Bank, World Health Organization, World Health Organization Family of International Classifications Collaborating Centre, Rehabilitation

International, United Nations Economic and Social Commission for Asia and the Pacific, United Nations Economic and Social Commission for Western Asia, United Nations Economic Commission of Europe, and United Nations Statistics Division.

Governmental Organizations of Persons with Disabilities: Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência-CORDE/Brazil and Secretaria Nacional para la Integración de las personas con Discapacidad SENADIS/Panama.

Meeting Summaries / major outcomes:

First meeting: February 18-20, 2002 in Washington, DC, USA

It was agreed that: 1) it is important and possible to craft internationally comparable general disability measures; 2) short and long set(s) of measures that are inter-related are needed; 3) ICF model will be used as a framework in developing disability measures; and 4) census questions are the first priority 5) next steps were established.

Second meeting: January 9-10, 2003 in Ottawa, Canada

A link was established between the purpose/s of a general disability measure and aspects of measurement. A conceptual matrix was developed linking the purpose of a general 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: February 19-20, 2004 in Brussels, Belgium

It was agreed that disability is multidimensional, thus, we cannot ascertain the single “true” disabled population. Different purposes are related to different dimensions of disability or different conceptual components of disability models. A position paper outlining major classes of purposes of an internationally comparable general disability measure and prioritizing the purpose of equalization of opportunities was discussed by the group. Equalization of opportunities was agreed upon and selected as the purpose for development of an internationally comparable general disability measure. A set of appendices accompanied the paper, the first provided ICF terms and definitions of the relative ICF concepts; the second provided guidelines for translating those concepts into survey measurement items. 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 general disability measure and to propose an approach for developing extended measurement sets related to the general disability measure. Finally, a plan for WG governance was adopted.

Fourth meeting: September 29-October 1, 2004 in Bangkok, Thailand

Major outcomes of the 4th WG meeting were: 1) conceptual agreement on a draft set of questions for the general disability measure, but wording revisions were required prior to pre-testing; 2) formation of a new workgroup operating in conjunction with a consultant to develop six implementation protocols for pre-testing the short set(s) of disability

measures; 3) begin development of the first extended measurement set; and 4) formation of a new workgroup on methodological issues.

Fifth meeting: September 21-23, 2005 in Rio de Janeiro, Brazil

The fifth meeting was hosted by Instituto Brasileiro de Geografia e Estatística (IBGE), in collaboration with CORDE. The meeting was attended by 47 persons representing 31 countries (from Africa, Asia, Europe, North America, Oceania, and South America), 2 organizations of persons with disabilities (Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência-CORDE/Brazil, and Secretaria Nacional para la Integración de las personas con Discapacidad-SENDIS/Panama and 5 international organizations (Inter-American Development Bank, World Bank, World Health Organization, World Health Organization Family of International Classifications Collaborating Centre, and United Nations Statistics Division).

Objectives for the 5th meeting were to:

- 1) Present work on the continued development of the census disability measure.
- 2) Present work on the written protocols and plans for implementing the census disability measure including lessons learned from regional workshops.
- 3) Present work on the development of extended measurement sets and the associated papers.
- 4) Discuss methodological issues related to proxy and non-response and to continue discussion of full population coverage.
- 5) Discuss strategic issues.

The meeting was organized into ten sessions. There were several key outcomes of this meeting. Potential revisions were discussed to the workgroup developing the census disability measure. Revisions were suggested for questions on communication, cognition, and hearing. Revisions were also recommended to the rationale, including clarifying the issue of seriousness/severity of disability. In addition, suggestions were made to make the language used in rationale consistent with ICF terminology.

Preliminary results from the WHO/ESCAP were presented and discussed. It was suggested that analyses based on WHO/ESCAP tests would contribute to the WG work since these tests used the short set of questions. Much of this analysis used the WHODAS questions as gold standard and concerns were raised about this practice. In this context, access to raw data was requested as it would be more useful than summaries of analyses.

Another suggestion was to evaluate the effect of question order on prevalence when the short set is placed on a larger survey. This workgroup also considered developing a short set of questions as a screener for future work, as well as conducting parallel analysis for countries with surveys that contain the four core disability questions embedded in an expanded set of questions on disability.

Several revisions to the implementation plans were suggested. The revisions include mention of use of a purposive sample in the instructions for the cognitive test and clarification in the cognitive protocol regarding in-country analyses versus cross-country analyses. The WG will carry out an analysis of the cross-country results and will write a report on this. It was also suggested that revisions to the enumerator training manual be made so that it meets the specific purposes of the WG. It was suggested that the workgroup provide an explanation as to why a conceptual translation method was chosen over backward-forward translation method. The workgroup will add instructions in the field test guide for ordering additional questions and documenting key characteristics of country practices for purposes of analysis. Most importantly, the workgroup suggested that the terminology across documents be made more consistent, specifically in the main implementation document. Regarding the inclusion of WHODAS and WHS questions in the WG pre-test it was suggested that the original WHODAS question phrasing should be used, but some participants expressed concern about the question wording.

The workgroup on extended measures was charged with the development of a plan (blueprint) for extended sets that would address the purpose, rationale, justification for the set along with issues of international comparability. The workgroup will also formulate possible options for adding domains to the measurement of equalization of opportunities. Furthermore, this workgroup will also begin development of an extended set on environmental questions. In this regard, Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência-CORDE is willing to work with the WG to develop environmental questions.

Several additional recommendations were made through the course of the meeting. Most notably among them was to form a new workgroup on analysis. During the meeting this new workgroup was formed in order to plan analyses that will inform the WG work on the short set(s) of disability measures. In particular, this workgroup will study the field and cognitive testing results for the WHODAS and World Health Survey to see if this can inform results of WHO/ESCAP and WG trials.

Furthermore, the WG supported the systematic and regular collection, by UNSD, of information on country activities in the area of disability statistics. It was agreed to make changes in the annual country reports used by the WG for collecting information on disability data collection so that there is no overlap with UNSD. UNSD would also continue the work with the WG on the impact of measurement on prevalence estimates of disability. Finally, in terms of future meetings, the possibility of holding a regional meeting in Central Asia / Middle East or Europe was suggested. Also, Ireland has expressed interest in hosting the Washington Group meeting in 2007.

The chair reported on a letter received from the WHO Network of Collaborating Center for the Family of International Classifications (WHOFIC) expressing concerns regarding inconsistencies in the use of the ICF framework by the WG and inviting WG to make a presentation at the next WHOFIC meeting in Tokyo. The concerns were echoed by the WHO representative during the meeting but strong disagreement with this position was expressed by other participants. A presentation was made on how the WG interprets the

use of the ICF framework and it was agreed that the chair would use this as the basis of her presentation at the WHOFIC meeting in Tokyo in October 2005.

Key agreements of the meeting and next steps:

- 1) Potential revisions to the short set of questions and the statement of rationale were outlined.
- 2) Development of a screener will be initiated at a future date. As a first step, analyses of existing data will be conducted in countries that have survey data on disability that include the WG short set(s) of disability measures. This information will be used to inform efforts to develop a screener.
- 3) Revisions to the implementation protocols were specified. The workgroup will proceed with updating the protocols as recommended. The workgroup will continue to assist countries to carry out the WG pre-tests.
- 4) The workgroup on extended measures was charged with formulating a plan (blueprint) for carrying out development of the extended sets including the purpose, rationale, justification, and international comparability. The group was also charged with formulating options for additional domains to measure equalization of opportunities and recommending domains for inclusion on an extended measure. The group is to begin development on an extended measurement set on environmental measures.
- 5) A new workgroup on analysis was formed to plan analyses of the WHO/ESCAP and WG tests.
- 6) Additional agreements included a plan to assess the issue of question order when the short set(s) of disability measures is placed on a larger survey.

Objectives for the 6th meeting are to:

- 1) Present work on the continued development of the short set(s) of disability measures including revisions based on the results of pre-testing (both WHO/UNESCAP test and WG test).
- 2) Present further revisions to implementation protocols.
- 3) Present work on the development of the extended measurement set/s including the plan for development of extended sets; the options for additional domains to be included to address the purpose of assessing equalization of opportunities; and the development of an extended set on environmental factors as barriers or facilitators.
- 4) Report on WG pre-test results; present analyses from WHO/ESCAP and WG pre-test along with recommendations.
- 5) Report on regional meetings (if any).
- 6) Discuss strategic issues.

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/citygroup.htm>).

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