

Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 6th Annual Meeting

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. The aim is to provide basic necessary information on disability which is comparable 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) has 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 (<http://www.cdc.gov/nchs/citygroup.htm>) and scientific presentations.

Year organized: 2001

Participants:

Representatives of national statistical offices, international organizations, organizations representing persons with disabilities, and other non-government organizations have participated in the last 6 meetings.

Current country representatives include (from national statistical offices): Albania, Argentina, Australia, Austria, Armenia, Barbados, Belgium, Bermuda, Bolivia, Brazil, Cambodia, Canada, Chile, China (Hong Kong Special Administrative Region, Macao Special Administrative Region, and Mainland), Columbia, Cuba, Czech Republic, Democratic Republic of Congo, Denmark, Egypt, Finland, France, Gambia, Ghana, Greece, Guatemala, Hungary, India, Iran, Iraq, Ireland, Israel, Italy, Ivory Coast, Japan, Jordan, Kenya, Latvia, Lebanese Republic, Lesotho, Lithuania, Malawi, Mauritius, Mexico, Micronesia, Mongolia, New Zealand, Norway, Occupied Palestinian Territory, Panama, Paraguay, Peru, Philippines, Poland, Romania, Serbia and Montenegro, Sierra Leone, Slovenia, South Africa, Spain, Saint Lucia, Sweden, Syria, Tanzania, Thailand, The Netherlands, Turkey, Tonga, Trinidad, Uganda, United Kingdom of Great Britain and Northern Ireland, United States of America, Venezuela, Viet Nam, Zambia, and Zimbabwe.

Current non-government organizations include: European Disability Forum, Rehabilitation International, Inter-American Institute on Disability, EUROSTAT, International Labor Organization, Organization for Economic Cooperation and Development, National Disability Authority-Ireland, Inter-American Development Bank, International Development Project,

World Bank, World Health Organization, 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) in Brazil, Secretaria Nacional para la Integración de las personas con Discapacidad (SENADIS) in Panama, and Disabled Organization for Legal Affairs and Social Economic Development (DOLASED) in Tanzania.

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 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: January 9-10, 2003 in Ottawa, Canada

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: February 19-20, 2004 in Brussels, Belgium

Since disability is multidimensional, it is not possible to ascertain the single “true” disabled population. Different purposes 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: 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 of disability measures; 3) begin development of the first extended measurement set; and 4) formation of a new workgroup on methodological issues.

Regional workshops: 1) June 20-22, 2005 in Nairobi, Kenya; 2) September 19-20, 2005 in Rio de Janeiro, Brazil

The Washington Group held two regional workshops in 2005, in Africa and Latin America, primarily directed toward countries in the region who were interested in including disability questions in their national censuses. The workshops familiarized countries in the region with the short set of WG questions on disability, the accompanying rationale, and the procedures for pre-testing the questions.

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

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: October 10-13, 2006 in Kampala, Uganda

The sixth meeting was hosted by the Uganda Bureau of Statistics (UBOS). The meeting was attended by 27 persons representing national statistical authorities from 22 countries, representatives from 5 international organizations (UNSD, UNESCAP, ILO, World Bank, SINTEF Health Research), as well as 39 participants from the Uganda Bureau of Statistics and organizations representing persons with disability in Uganda. Specifically, representatives from the following national statistical offices participated: France, Canada, Lesotho, South Africa, Czech Republic, Egypt, USA, Democratic Republic of the Congo, Tanzania, Ireland, Mauritius, Paraguay, Brazil, United Kingdom, Bermuda, Zimbabwe, Mexico, Argentina, Philippines, Kenya, Vietnam, and The Gambia. Representatives of organizations within Uganda included: the National Union of Persons with Disabilities in Uganda, Uganda National Association of the Deaf, Epilepsy Support Association, Action on Disability & Development, Makerere University, Kyambogo University, WHO (Uganda), Ministry of Health (Disability Unit), Ministry of Gender, Labour, and Social Development, Ministry of Finance, Planning and Economic Development, Uganda Action on Physical Disability, UNDP (Uganda), Forum for Disabled Recovery Association, Uganda Mental Health Unit, Uganda Society for Disabled Children, Parliament (Women's Disabilities, Uganda), National Union of Disabled Persons, UNDP Mine Action (Uganda), and the National Center for Disability. The external consultant from the United States evaluating the Washington Group's use of the World Bank funds attended the meeting as part of her assessment.

Objectives for the 6th meeting were to:

- 1) Report on WG pre-test results; present analyses from WHO/ESCAP and WG pre-test along with recommendations.
- 2) Present work on the continued development of the short set of disability measures including revisions based on the results of pre-testing (both WHO/UNESCAP test and WG test).
- 3) Present further revisions to implementation protocols.

- 4) 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.
- 5) Report on regional meetings (if any).
- 6) Discuss strategic issues.

Workgroup on the short set

The meeting was organized into seven sessions. There were several key outcomes. 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). These questions were based on the model of disability inherent in the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) with a particular eye to international comparability. The workgroup on the short set will consider minor revisions to the question set within the next few months. Specific issues that were of concern included the clause for the vision and hearing questions, the length of the communication question, and the introduction to the question set (which may be influenced by changes to the communication question). More specifically, some respondents had difficulty understanding the glasses clause, and its location within the question seemed to pose a problem in some cases (for instance, respondents focused on whether or not they wore glasses and responded accordingly). It was also suggested that the preamble to the communication question ("Because of a physical, mental or emotional health condition") be moved to the introduction to the question set since the length of this question posed a problem for respondents. In addition, the WG asked the workgroup to develop an alternative (optional) question on upper body function. The workgroup was also charged with addressing the use of the short set as a screener. This work will be assigned to a subgroup of the workgroup.

Workgroups on analysis and methodological issues

Although detailed analyses of the pre-test data were presented at the meeting, the WG agreed that there is much more analytical work that can be done that would be informative. The workgroup on data analysis was charged with completing this work. First, additional analyses with WHO/UNESCAP were recommended to identify reasons for discrepancies and commonalities in the results that were presented. Next, the workgroup will evaluate issues raised by the data from Viet Nam in order to determine the reason for disparities between responses to questions on vision, hearing and self care, particularly for respondents that answered "unable" to one or more of the extended questions. The workgroup will also evaluate the proxy data and evaluate responses for children. Additional analyses are to be conducted with the field test data. The workgroup will evaluate how the WG questions work relative to socio-economic and demographic factors. Additional work will include an examination across domains of functioning in order to get a better understanding of potentially problematic response patterns (especially for self care), investigating profiles of subgroups defined by functioning status, and evaluating subpopulations that the WG questions might miss using the data from Zambia.

Both of these workgroups (on the short set and data analysis) will jointly plan and oversee publication of the pre-test results. The publication/s will include a description of the pre-test

process, the results of the tests, the strengths and limitations of the data set, comparisons to other work, examples of country experiences conducting the test, and identification of issues requiring further research.

Three issues were raised by the workgroup on methodological issues: 1) Portability of questions across administration modes; 2) How the questions work for specific subpopulations such as those with severe disability, children, or the institutionalized population; and 3) The use of proxy informants. It was decided that the methodological workgroup would be merged with the data analysis workgroup to address these specific issues through additional analyses of the pre-test data. It was agreed that proxy reporting and mode portability are priorities for the group.

Workgroup on extended sets

The workgroup on the extended measurement set/s is large and it was agreed that the group needed to self-organize in order to complete their work in the most efficient and effective way. A formal proposal will be written for each major task undertaken by the group. Two additional countries volunteered to work with this group; Canada and Bermuda. UNESCAP expressed the desire to work with this group since development of extended sets is in their work program and if they receive funding for this, they will be able to put considerable effort toward the work which might speed the process. The workgroup was charged with drafting a position paper specific to developing an extended question set for the purpose of assessing equalization of opportunities. The position paper will include the plan, purpose, and approach for developing the extended set. It was agreed that the primary issue for this extended set is expansion of the existing domains covered in the short set and adding to the existing domains if deemed appropriate. There was discussion regarding whether there should be a separate subgroup to address questions on the environment or if these questions should be incorporated into the expansion of domain specific questions. This will be decided by the group. The group will review and select existing questions for the proposed extended set and will conduct pre-tests if time allows. If UNESCAP receives funding for its work program, the WG may be able to conduct pre-tests in at least one region.

Workgroup on implementation

This workgroup was disbanded because their work was completed.

Next steps

- 1) The workgroup on the short set is to consider additional revisions to the short set of questions as outlined and address the issue of using the short set as a screener.
- 2) The workgroup on analysis is to continue analysis of pre-test data as outlined.
- 3) Both of these workgroups (workgroup on the short set and workgroup on analysis) are to organize and oversee publication of the test results.
- 4) The workgroup on extended measures was charged with self-organizing in order to accomplish their work, and drafting a position paper specific to developing the first extended set with a purpose of equalization of opportunities. The paper should include a plan and approach (blueprint) for carrying out development of the extended set including the purpose, rationale, and justification for the extended set as well as the issue of international comparability. The group was charged with adding questions on the existing domains and adding domains as appropriate to assess equalization of

opportunities. The group is to review and select existing questions and pre-test the question set if time permits.

- 5) The workgroup on methodological issues was merged with the workgroup on data analysis to address specific issues such as: 1) evaluating the proxy data (workgroup priority); 2) determining how the questions work for specific subpopulations such as children and determining the age at which the questions are meaningful by evaluating the pre-test data from children; and 3) determining the portability of questions across administration modes.
- 6) The WG Secretariat agreed to draft the UN Statistical Commission report, the usual executive summary of the annual meeting, a 4-page summary of pre-test results to inform governmental agencies, and a more general document describing how to use and interpret the data including a plan to address the issue of special populations (children, etc.).

The 7th WG meeting will be held September 19-21, 2007 in Dublin, Ireland. Objectives for the 7th WG meeting are to:

- 1) Present additional work on short set:
 - a) Present results of additional pre-testing (if any)
 - b) Present results of additional analyses of pre-test data
 - c) Present any revisions to original six questions
 - d) Present work on use of short set as a screener
 - e) Present option for measuring upper body function
- 2) Present proposal for extended set and test results if available.
- 3) 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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