

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 small set(s) of general 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 principles 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 general measure(s). 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, general 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 4 meetings.

Current country representatives include: Australia, Austria, Belgium, Brazil, Canada, Columbia, Czech Republic, Denmark, Egypt, Estonia, Finland, France, Greece, Hong Kong (China), Hungary, India, Ireland, Israel, Italy, Latvia, Macao (China), New Zealand, Norway, Palestine, Peru, Philippines, Poland, Romania, Sierra Leone, Slovenia, South Africa, Spain, St. Lucia, Sweden, The Netherlands, Turkey, Uganda, United Kingdom, and the United States.

Current international and non-government organizations include: European Disability Forum, Eurostat, International Federation for Spina Bifida and Hydrocephalus, International Development Project (IDP), International Labor Organization (ILO), Organization for Economic Cooperation and Development (OECD) Health Policy Unit, Partnership Health EU, Rehabilitation International, United Nations Statistics Division, United Nations Economic Commission for Europe (UNECE), United Nations Economic and Social Commission for Asia and the Pacific (ESCAP), United Nations Economic and Social Commission for Western Asia (ESCWA), World Bank, and World Health Organization (WHO).

Past meetings / 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 general 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.

Products:

Proceedings (presentations and papers) from the first three meetings, 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>).

Report of the 2004 meeting:

The fourth meeting of the Washington Group on Disability Statistics (WG) was held September 29 – October 1, 2004 in Bangkok, Thailand, hosted by UNESCAP and the Thai National Statistical Office. The meeting was attended by 40 persons representing 23 countries (Africa, Asia, Europe, Middle East, North America, Pacific, South America), and 5 international organizations (UN and affiliates, World Bank, ILO, WHO, Rehabilitation International). The meeting was organized in 7 sessions comprised of presentations of draft position papers followed by focused discussion addressing specific

session objectives. Session outcomes included key agreements, products, and a work plan. Objectives for the 4th meeting were to:

- 1) Present work on development of the general disability measure (workgroup 1).
- 2) Discuss the proposed plan for implementing the general disability measure (workgroup 2).
- 3) Discuss the proposed approach for development of extended measurement sets (workgroup 3).
- 4) Discuss methodological issues related to full population coverage.
- 5) Discuss strategic issues.

There were several key outcomes of the meeting. First, a draft set of questions for the general disability measure was agreed upon conceptually, but wording revisions are required prior to pre-testing. Workgroup 1 (on the general measure) will revise wording of the proposed questions with input from WG members and decide on the final questions, including clarification of revisions made, by December 2004. The question set will undergo cognitive and pre-testing. Issues requiring testing were delineated. Questions based on six domains at the borderline of the ICF components of body functions/impairments and activities/limitations will be pre-tested as potential candidates for inclusion; four domains are considered the core (walking, seeing, hearing, and cognition), but two additional domains will also be examined (self-care and communication). A severity scale will be used in the response categories.

A new workgroup (on implementation) was formed to develop six protocols necessary to effectively implement the general disability measure. The protocols include: 1) establishing objectives and an evaluation plan for cognitive and pilot testing; 2) establishing plans for report writing including tabulation and analysis; 3) establishing plans for cognitive testing; 4) translation; 5) enumerator training; and 6) sample design issues (such as the number of households to be covered and identification of other census questions to be included with the disability questions on the pilot test). Existing protocols, such as the UN guidelines and the EU translation protocol will be used for reference. The protocols are to be completed in a four month timeframe. Countries willing to participate in pre-testing were identified. In view of the comprehensive work involved in the development of these protocols and the strict deadlines, the WG proposed that this group should work in conjunction with a consultant.

Workgroup 3 (on extended measurement sets) will initiate development of the first two extended sets of measures on disability. It was agreed that the purpose of the extended measurement sets is assessment of equalization of opportunities. The extended sets are intended as modules that will go into other existing national surveys. The workgroup will develop one extended set of questions expanding on the six domains identified for the short general measure (more detail) and adding questions on domains that reflect other basic activities. A second extended set will be developed encompassing more complex activities/limitations, participation/restrictions and environmental factors. The justification for the extended sets will be specified. This workgroup will also identify indicators that will be used to demonstrate equalization of opportunities. For the next meeting, members of this workgroup will develop a paper examining the domains of

participation and environment and how they relate to existing questionnaires in population wide surveys.

The WG agreed that the issue of persons excluded from national surveys is important and that differences in subpopulations that are excluded from national surveys across countries may affect the comparability of disability measures. A new workgroup on methodological issues was formed to address the topic of full population coverage as well as other methodological issues including the effects of proxy and non-response, the effects of questionnaire administration mode, and the potential for harmonization of health and disability data using modern calibration techniques. Additional questions will be included on the next country report to identify groups excluded from national surveys. At the next meeting, the workgroup will examine whether it is feasible to include these subpopulations and whether the proposed questions on disability are relevant for these populations.

UNSD will work on analyzing the WG country reports to better understand disparate prevalence estimates on disability. They will report on this work at the 5th WG meeting. The 5th WG meeting will be held September 21-23, 2005 in Rio de Janeiro, Brazil.

Objectives for the 5th WG meeting are to:

- 1) Present work on continued development of the general disability measure including revisions based on the results of cognitive and pre-testing (workgroup on general measure);
- 2) Present work on the written protocols and plan for implementing the general disability measure including lessons learned from pre-testing (workgroup on implementation);
- 3) Present work on the development of the extended measurement set and the associated paper on its' relationship to participation and the environment (workgroup on extended measures);
- 4) Discuss methodological issues related to proxy and non-response and to continue discussion of full population coverage (workgroup on methodological issues);
- 5) 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. Executive summaries of last three meetings are posted on the WG website along with presentations and papers from the meetings:
<http://www.cdc.gov/nchs/citygroup.htm>

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