Executive summary for the UN Statistical Commission

The third meeting of the Washington Group on Disability Statistics (WG) was held on February 19-20, 2004. The meeting was attended by 50 persons representing 30 countries (Africa, Asia, Europe, North America, South America) and 11 international organizations (such as the European Disability Forum, Eurostat, ILO, OECD, UN, WB, WHO).

Objectives and agenda

The objective of the meeting was mainly strategic. The meeting was opened by Marleen De Smedt (Eurostat) who reviewed the objectives and activities of the WG to date. Hans d'Hondt, Director General of the Belgium National Institute on Statistics, welcomed the group. Mrs. Wallis Goelen (EU Policy Department) then reviewed the EU policy on disability. The main agenda items discussed were:

- **Selection of purposes**: Based on the disability matrix presented at the second meeting in Ottawa, a position paper was presented followed by three related commentary papers. The discussion focused on the selection of 1 or 2 purposes that the general disability measure should address and the rationale for the choice based on relevance with respect to policy and feasibility of implementation, with special attention to the international comparability of disability data.
- **Strategy and organization of the WG work**: In order to be effective in accomplishing the three main objectives of the WG (short general disability measure, set of extended measures, related methodological issues) and in order to produce tangible and useable end products, it has become increasingly apparent that an organizational plan for the governance (i.e. structure and operation) of the WG is needed. A plan for governance was presented followed by three commentary papers and a plenary discussion.
- **Next steps**: Practical decisions were made about the next meeting (such as place, dates, objectives, and responsible persons for the work to be done between meetings).

Action steps - Each session during the meeting produced action steps. The actions are in bold print after highlighting the important decisions of each session.

Proposed Purpose of an Internationally Comparable General Disability Measure

*Chair*: Marijke de Kleijn (Netherlands)

*Rapporteur*: Niels Rasmussen (Denmark)

*Presenters*: Jennifer Madans and Barbara Altman (USA)

*Authors of paper*: Jennifer Madans, Barbara Altman, and Elizabeth Rasch (USA); Margaret Mbogoni, Malin Synneborn, and Jeremiah Banda (UN); Angela Me (UNECE); and Elena DePalma (ISTAT)

*Commentators*: Alicia Bercovich (Brazil); V.M. Tamhane (India); and Genara Rivera (Peru)

a) There was concurrence of the WG to give highest priority to purpose 3, equalization of opportunity, as the purpose for an internationally comparable general disability measure.
The group will attempt to work on purpose 2 simultaneously (monitoring the level of functioning in the population).

b) A workgroup (Workgroup 1) was designated to generate a draft set of questions related to this purpose (short form) to be completed by the summer of 2004. This group was charged with developing a list of measurement domains and criteria to rank domains for potential inclusion, determining if inclusion of a severity indicator is necessary, addressing the issue of accommodations, and if time allows, the group will pilot the proposed questions. The UN will help to identify countries in which piloting could be carried out. Workgroup 1 is composed of:

Barbara Altman (USA)   Emmanuelle Cambois (France, Euro-Reves)
Jennifer Madans (USA)  Nenad Kostanjsek (WHO)
Elizabeth Rasch (USA)  Herman Van Oyen (Belgium)
Jeremiah Banda (UN)    Elena De Palma (Italy)
Malin Synneborn (UN)   V.M. Tamhane (India)
Ahmed Hussein (UN-ESCWA)  Romulo Virola (Philippines)
Angela Me (UNECE)     Carlotta Besozzi (European Disability Forum)
Alicia Bercovich (Brazil)  Representative from Australia (to be determined)
Renée Langlois (Canada)

c) A second workgroup (Workgroup 2) will prepare a paper for the next meeting proposing method/s for implementing the general disability measure (short form). Elements of the proposal will address the issues of pilot testing, translation, enumerator training, and comparability. Workgroup 2 is composed of:

Herman Van Oyen (Belgium)
Nenad Kostanjsek (WHO)
Howard Meltzer (UK)
V.M. Tamhane (India)
Representative from Euro-Reves (to be determined)

d) A third workgroup (Workgroup 3) will prepare a paper proposing an approach for development of extended measurement set/s related to the general disability measure/s. Workgroup 3 is composed of:

Marijke de Kleijn (Netherlands), Chair
Don Lollar (USA)
Representative from Australia (to be determined)
Representative from Euro-Reves (to be determined)
Representative from international disability organization (to be determined)

Governance
Chair: Gary Catlin (Canada)
Rapporteur: Jacques Bonte (Partnership Health EU)
Presenter: Renée Langlois (Canada)
Authors of paper: Jennifer Madans, Barbara Altman, and Elizabeth Rasch (USA); Renée Langlois (Canada); and Elena De Palma and Roberta Crialesi (Italy)
Commentators: Romulo Virola (Philippines); Helen Namirembe-Nviiri (Uganda); and Howard Meltzer (UK)
a) A plan for governance was adopted by the WG. **The governance plan will be revised according to the discussion at the meeting within one month of the meeting (approximately March 22, 2004).**
b) Representative/s will be appointed by the national statistical authorities of member states.  
c) Adjunct members may participate in the activities of the WG. Adjunct members include well-recognized international organizations with a formal relationship to national statistical authorities such as disability organizations, UN affiliates, other statistical agencies (i.e. OECD), organizations that represent national statistical agencies (i.e. Eurostat), and other groups with international expertise in disability statistics.
d) There will be representation of persons with disabilities in the WG. In addition to the European Disability Forum who already participate in the WG, **international disability organizations will be identified and invited to participate before the next meeting.**
e) NCHS (USA) was selected as the Executive Secretariat of the WG.
f) **The Steering Committee and chair will be responsible for implementing governance procedures.** Members of the Steering Committee were selected and include the past three meeting hosts (representatives from the United States, Canada, Eurostat), the next meeting host (to be named), and regional representatives from Brazil, Uganda, the Philippines, and Egypt. The Steering Committee selected Jennifer Madans (NCHS, USA) as chair for a one-year term.
g) **The Steering Committee was charged with development of a long-range work plan and timeline for implementation of the work plan to facilitate WG activities.** The Steering Committee is to circulate the work plan to the WG membership prior to the next annual meeting.

**Report on World Bank Activity**  
**Presenter:** Daniel Mont (World Bank)  

a) The status of the proposed grant from the World Bank for strengthening disability statistics internationally, or Development Grant Facility (DGF), was discussed. The World Bank’s interest in the link between disability and poverty was indicated. In the event of funding, the possibility of grant renewal was discussed along with the implications for the products and timing of WG activities.

**General issues**  
**Chair:** Eva Gardos (Hungary)  
**Rapporteur:** Don Lollar (USA)  

a) The objectives for the next meeting were specified and include the following:  
1. Present the work on the draft general disability measure developed by Workgroup 1.
2. Discuss the position paper on implementation submitted by Workgroup 2.
3. Discuss methodological issues of full population coverage, based on papers already prepared by Howard Meltzer and colleagues.
4. Discuss the position paper on extended measurement sets submitted by Workgroup 3.
5. The Steering Committee chair will lead a discussion on strategic issues, such as the status of the World Bank proposal, identifying the WG representative to the UN Statistical Commission meeting, timeframes, etc.

b) **We hope to hold the next meeting in September or October, 2004 in Bangkok in conjunction with ESCAP.** The 2005 meeting is planned to be held in Brazil. If the
Bangkok venue is not available in 2004, Brazil and Geneva were discussed as possible backup venues.

Marleen DeSmedt, convener, ended the third Washington Group meeting by reflecting that the agenda was noteworthy for its open discussion and non-hurried framework. She noted the urgent need across the globe for a general disability measure and indicated that the WG will soon be able to provide such a measure. Finally, she indicated that the need for a structured governance process had been addressed during the meeting.

*Executive summary prepared by*: Marijke de Kleijn (Netherlands); Don Lollar (USA); and Elizabeth Rasch (USA)
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