International Seminar on the Measurement of Disability

New York
4-6 June 2001

Agenda
United Nations International Seminar on Measurement of Disability
New York, 4-6 June 2001

Objectives

The meeting will bring together a broad array of developed and developing country experts in disability measurement for statistical reporting:

- Review and assess current status of methods used in population-based data collection activities to measure disability in national statistical systems. Particular attention will be given to questionnaire design;
- Develop recommendations and priorities to advance work on measurement of disability;
- Contribute to building a network of institutions and experts, including producers and users of disability statistics to implement the developments in this field.

The work to achieve these objectives should build on accepted international standards and guidelines, as reflected in the Background Documents for the meeting.

Participation

Participants will include mainly statisticians from designated offices in national statistical systems. All regions will be represented. Representatives of the disability community, other users of disability data, survey methodologists and international organizations – whose work is consistent with the objectives of the meeting - will also participate.

Background Documents

International Recommendations, Classifications and Guidelines

- “Guidelines and principles for the development of disability statistics”, Unedited copy of future United Nations publication
- Principles and Recommendations for Population and Housing Censuses, Revision 1, United Nations publication, Sales No. E.98.XVII.8
- Manual for the Development of Statistical Information for Disability Programmes and Policies, United Nations publication, Sales No. E.96.XVII.4
- “International Classification of Functioning, Disabilities and Health” (ICIDH-2), Pre-final draft, December 2000, WHO/EIP/GPE/CAS/ICIDH-2 PF, 00.1
- ICIDH-2 Resolution EB107.R15 approved by the WHO Executive Board on 22 January 2001
Regional Material

- EUROSTAT Working Papers
  Survey Data on Disability
  Coverage of Health Topics by surveys in the European Union
- *Health Interview Surveys*, WHO Regional Publications, European series, No. 58
- “An inventory of health and disability-related surveys in OECD countries”, OECD Labour Market and Social Policy-Occasional Papers, No. 44
Work Programme

Monday 4 June
Morning

8:30-9:00 a.m.  Registration

9:00-9:30 a.m.  Opening Session: Rationale and objectives of the meeting

Presenters: Nitin Desai, Under-Secretary General, United Nations Department of Economic and Social Affairs (DESA)
Hermann Habermann, Director, United Nations Statistics Division (UNSD), DESA
John Langmore, Director, Division for Social Policy and Development, DESA

9:30-10:00 a.m. Break

10:00 a.m.-12:30 p.m. Session 1: Concepts and objectives for the measurement of disability

Objective: To introduce the history of the development of disability statistics and definitions and to describe the uses of disability statistics at national, regional, and international level.

Chair: Shuaib Chalken, Director, Office on the Status of Disabled Persons, South Africa
Discussant: Marijke W. de Kleijn-de Vrankrijker, TNO Prevention and Health, The Netherlands
Presenters: Yerker Andersson, National Council on Disability, USA: Views of the disability community
Winifred Hellen Akot, Ministry of Gender, Labour and Social Development, Uganda
Andre Gubbels, European Commission
Mary Chamie, UNSD: Historic overview of developments of disability statistics and definitions

Monday 4 June
Afternoon (2:00 - 5:30)

2:00-3:30 p.m. Session 2: National experiences in the development of instruments to measure disability

Objective: To provide an overview of instruments used to collect disability data at national level and to review and assess the adequacy of and gaps in these instruments in relation to the ICIDH-2

Chair: Scott Campbell Brown, US Department of Education
Discussant: Marleen de Smedt, Eurostat
Presenters: Kristine Mulhorn, Renee Langlois, Paul Placek and Gretchen Swanson, DISTAB
Niels Rasmussen, National Institute of Public Health, Denmark: Overview of Data Collection Practices in 29 Developed Countries (OECD and
3:30-3:50 p.m.  Break

3:50-5:30 p.m. Session 3: **International initiatives in the measurement of disability and statistical techniques to improve analysis of data**

*Objective:* To review and assess the adequacy of and gaps in instruments initiated by international organizations for the development of standards and guidelines to measure disability in relation to the ICIDH-2; overview of techniques to harmonize output data

*Chair:* Ros Madden, Australian Institute of Health and Welfare

*Discussants:* Jacques Bonte

*Presenters:*
- Gerry Hendershot, National Center for Health Statistics, USA: *Analytical overview of instruments and guidelines developed by international organizations*
- Jan van Rijckevoorsel, TNO, The Netherlands: *Overview of techniques to harmonize data across time and space*

**Tuesday 5 June**

**Morning**

9:00-10:30 a.m. Session 4: **Implications of the new “elements” of the ICIDH-2 for measurement of disability focusing on Environment and Participation**

*Objective:* To assess the current status of methodology in relation to the measurement of participation and environment

*Chair:* David Gray, Washington University, USA

*Discussant:* Patrick Fougeyrollas, University of Laval, Canada

*Presenters:*
- Gale Whiteneck, Craig Hospital, USA
- Ros Madden, Australian Institute of Health and Welfare
- Marguerite Schneider, WHO

10:30-10:50 a.m.  Break
Session 5: Questionnaire and survey design features for the collection of data from persons with disability

Objective: To review issues of survey methodology specifically related to the measurement of disability

Content: screening questions, global questions, response scale, questions wording, context effects, culture issues, self/proxy, mode of data collection, content

Chair: Vittoria Buratta, ISTAT, Italy
Discussant: Willem Frey, Westat, USA
Presenters: Renee Langlois, Statistics Canada
Ben Fuller, Namibia/Sekai Nhiwatiwa, Zimbabwe
Pakamas Rattanalunggarn, National Statistical Office, Thailand
Arpo Aromaa, National Public Health Institute, Finland

1:00-2:00 p.m. Guided Tour of UN Headquarters
UN Secretariat Building
[Visitor’s Entrance, First Avenue & 45th Street]

Tuesday 5 June
Afternoon (2:30 – 6:00 p.m.)

Session 6: Choosing a data collection mechanism: census or survey?

Objective: To present and assess experiences on mechanisms for collecting data on disability: censuses, special disability surveys, modules in general population surveys

Chair: Susan Schechter, Office of Management and Budget, USA
Discussant: Gabriel Fosu, UNFPA, Nigeria
Presenters: Ken Black, Australian Bureau of Statistics (ABS): Comparative analysis of censuses and surveys as instruments to collect data on disability
Monica Bartley, Jamaica: Pros and cons of data collected using a census: the experience of the Caribbean countries
Jaap Van den Berg, Eurostat: EU general population surveys

4:00-4:30 p.m. Break

Session 7: Concurrent working sessions on special population groups

Objective: To focus on additional (or specific) instruments needed to measure disability in special population groups
Children

Chair/Discussant: Rune Simeonsson, Chair of International Task Force for Children, ICIDH-2, University of North Carolina, USA

Presenters: Maureen Durkin, Columbia University, USA
Gareth Jones, UNICEF

Elderly

Chair/Discussant: Josefina Natividad, UP Open University, Philippines

Presenter: Ken Black, Australian Bureau of Statistics

Wednesday 6 June
Morning

9:00-10:30 a.m. Continuation of Session 7: Concurrent working sessions on special population groups

Cognitive and psychological functioning

Chair/Discussant: Cille Kennedy, Chair, International Mental Health Task Force for Children, ICIDH-2, DHHS, USA

Presenters: Vincent Campbell, Centers for Disease Control, USA
Carol Jagger, University Of Leicester, UK

Institutional population

Chair/Discussant: Renee Langlois, Statistics Canada

Presenters: Herman Van Oyen, National Institute of Public Health, Belgium
Pascale Roussel, CTNERHI, France

10:30-11:00 a.m. Break

11:00 a.m.-12:30 p.m. Session 8: Plenary discussion on special population groups, presentation by the chair/discussants of concurrent sessions

Chair: Don Lollar, Center for Disease Control, USA

Presenters: Rune Simeonsson, Chair of International Task Force for Children, ICIDH-2, University of North Carolina, USA
Cille Kennedy, Chair of the International Mental Health Task Force, ICIDH-2, DHHS, USA
Renee Langlois, Statistics Canada
Wednesday 6 June
Afternoon

2:00-4:00 p.m. Session 9: Panel discussion: review, summary and a bridge to the future.

Facilitator: Nancy Mathiowetz, University of Maryland, USA

Panelists: Hermann Habermann, Director, UNSD
Jennifer Madans, National Center for Health Statistics, USA
Michail Skaliotis, Eurostat