

**United Nations Statistics Division
United Nations Children's Fund
Statistical Office of the European
Communities
Centres for Disease Control and Prevention**

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18 May 2001

**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
- *International Standard, ISO 9999, Technical Aids for Disabled Persons: Classification, 1st ed.* International Organization for Standardization, 1992, Geneva, ISO. Prepared by Technical Committee ISO/TC 173
- 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

Eurostat documents)

Angela Me and Margaret Mbogoni, UNSD: *Overview of Data Collection Practices in Less Developed Countries*

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
Alan Tennant, University of Leeds, UK

Presenters: Gerry Hendershot, National Center for Health Statistics, USA: *Analytical overview of instruments and guidelines developed by international organizations*

Jan van Rijckevorsel, 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

10:50-12:30 a.m. **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 Rattanalungarn, 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.)

2:30-4:00 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**

4:30-6:00 p.m. **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