

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

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**International Seminar on the  
Measurement of Disability**

**New York  
4-6 June 2001**

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*(Provisional) 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, 1<sup>st</sup> 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:* Barbara M. Altman, National Center for Health Statistics, USA

*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 & 45<sup>th</sup> 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