# **Washington Group on Disability Statistics**

Omni Shoreham Hotel Washington, DC February 18-20, 2002 Agenda

Monday, February 18, 2002

8:30 - 9:00 AM: Registration / Continental Breakfast

9:00 - 12:00 AM: Morning Sessions

Morning Chairperson: Jennifer Madans, Associate Director for Science National Center for Health Statistics, USA

9:00 – 10:15 AM: Opening Session - Introduction and Overview Speakers: Ed Sondik, Director,

National Center for Health Statistics, USA

**Hermann Habermann**, Director, United Nations Statistics Division (UNSD) DESA

Jennifer Madans, Associate Director for Science,

**NCHS** 

Organization of the meeting and presentation of objectives

**Barbara Altman,** Special Asst. on Disability Statistics National Center for Health Statistics, USA Review of June 2001 Meeting at UN

10:15 - 10:35 AM: Break

10:35AM – 12:00 PM: Session 1 - Goal Setting and Agenda Adjustment
Discussion of proposed objectives; identification of other goals; suggestions for additional topics to be addressed in subsequent meetings; identification of outcome products.

Moderator: Jennifer Madans, Associate Director for Science National Center for Health Statistics, USA **Discussants:** Meeting Participants

12:00 – 1:30 PM: Lunch - On your own

1:30 – 5:30 PM: Afternoon Sessions

<u>Afternoon Chairperson</u>: Marijke de Kleijn-de Vrankrijker, TNO Prevention and Health, The Netherlands

#### 1:30 – 3:15 PM: Session 2 - Purpose of Measurement

Presentations on purpose of measurement and introduction of global measures and types of surveys or censuses used.

#### **Speakers:**

**Roberta Crialesi**, Coordinator of Health Statistics Office, ISTAT National Institute of Statistics, Italy

**Eva Gardos**, Director, Population, Health and Welfare Statistics Department, Hungary

**Bothaina El Deeb**, Professor, Head Population Studies and Research Center, Egypt

**Alicia Bercovich**, Coordinator of the 2000 Census Committee, JBGE-Instituto Brasileiro De Geografia Estatistica, Brazil

**Questions from Chair:** See notebook section Interactive discussion of purposes to be addressed and concepts that will need to be operationalized

#### 3:15 - 3:30 PM: Break

# 3:30 – 4:30 PM: Session 3 - An examination of the ICF Model

This session will update the group on the status of the development of questions to create measures in each of the domains of the model. An inventory of global instruments available in participating countries is provided in the notebooks and room documents.

# **Speakers:**

Bedirhan Ustun, World Health Organization, Geneva

**Emmanuelle Cambois**, Equipe Démographie et santé (EuroREVES), Montpellier, France

Niels Rasmussen, National Institute of Public Health, Denmark

4:30 – 5:30: Session 4 - Discussion of the U.N. standard disability tables from Principles and Recommendations for Population and Housing Censuses, Rev. 1 section on disability

This session will review the concepts, definitions, classifications of disability, as well as the suggested approach to collecting data on disability in the census recommendations and making revisions to these based on the ICF. In addition it will discuss the process that will monitor the implementation of these recommendations.

#### **Speakers:**

Margaret Mbogoni, United Nations Statistics Division

Angela Me, United Nations Statistics Division

**6:30: Group Dinner** - Registration and Payment must be received by noon 2/18 See Registration desk for details and menu.

Tuesday, February 19, 2002

8: 00 – 8:30 AM: Continental Breakfast

8:30 – 12:00 AM: Morning Sessions

Morning Chairperson: Richard Madden, Head, WHO Collaborating Centre for the Classification of Diseases, Australian Institute of Health and Welfare, Australia

# 8:30 – 9:40 AM: Session 5 - Global Measures of Disability

This session will discuss the types and numbers of questions that could usefully be used in census formats. Of particular concern would

be the impact of the cut point associated with limited questions on the estimates of disability that would result.

#### **Speakers:**

Joanne Hillermann, Australian Bureau of Statistics, Australia "The Australian Experience with a Disability Census Question"

Margaret Mbogoni, United Nations Statistics Division "Disability Census Questions, with an Emphasis on Developing Countries"

Questions from the Chair: See notebook section

**Next Steps** - This component of the session involves a discussion of possible next steps to address the issues that have been identified and which issues should be prioritized to be addressed in subsequent meetings.

9:40 - 9:50 AM: Break

# 9:50 – 11:10 AM: Session 6 - What is the Relationship of Global Measures to the ICF

This session will examine what components of the ICF are most useful for measuring disability in a more global context with limited questions. Are global measures of environment and participation possible? Are measures for separate populations possible in a Census context?

# **Speakers:**

Renee Langlois Statistics Canada, Canada

**Joanne Hillermann**, Australian Bureau of Statistics, Australia "Mapping of the Canadian and Australian Disability Survey Questions to the ICF"

**Questions from the Chair:** See Notebook Section

**Next Steps: -** Participants will identify questions of highest priority, what research projects or papers are called for in future sessions as well as possible countries/researchers to follow-up on individual

components or possible collaborations to address specific issues.

# 11:10 AM – 12:00 PM: Session 7 - Exploring the Confounding Function of Assistive Device Use

This session will explore the identification of disability and whether the lack of specification of assistive device use alters a true count of what is happening within a population. Does the lack of accurate consideration of all devices and their use compromise our measures? How does this impact on global indicators?

#### Speaker:

**Jennifer Madans**, Associate Director for Science National Center for Health Statistics, USA

Questions from the Chair: See Notebook Section

**Next Steps:** - Participants will identify questions of highest priority, what research projects or papers are called for in future sessions as well as possible countries/researchers to follow-up on individual components or possible collaborations to address specific issues.

12:00 – 1:30 PM: Lunch – On your own

1:30 – 5:30 PM: Afternoon Sessions

Afternoon Chairperson: Nayiga Florence Ssekabira, Minister of State for Elderly and Disability Affairs, Uganda

# 1:30 – 3:00 PM: Session 8 - What are the Unique Cultural Practices that Influence the Nature of the Environment or Prescribe or Proscribe Participation?

To ask participation questions in a culture that prohibits certain types of participation to certain members of the population is an exercise in futility. These presentations will address the cultural attitudes within which the questions must be framed. Do these cultural differences constitute a barrier to collecting comparable data?

# **Speakers:**

**Margie Schneider**, Technical Officer, Environmental Factors Task Force (ICF), World Health Organization, Geneva

Nora Groce, Associate Professor, Yale School of Public

Health

Questions from the Chair: See notebooks

**Next Steps** - Participants will identify questions of highest priority, what research projects or papers are called for in future sessions as well as possible countries/researchers to follow-up on individual components or possible collaborations to address specific issues.

3:00 - 3:30 PM: Break

3:30 – 5:00 PM: Session 9 - What are the Unique Cultural Issues that Act as Barriers to Collecting Data? Are there Common Barriers to Data Collection that Occur Cross-Culturally?

Possible topics include stigmatization, language barriers in multi language cultures, etc. How common are these across different cultures? What are the ways to involve persons with disabilities in the planning process and the things necessary to allow for their full participation?

**Session Moderator: Mr. B.Z. Gumede**, Executive Director, African Rehabilitation Institute (ARI)

**Speakers:** 

Herman van Oyen, Institute of Public Health, Belgium

**V.M. Tamhane**, Assistant Director, Office of the Registrar General, India

Questions from Chair: See notebook section

**Next Steps:** - Participants will identify questions of highest priority, what research projects or papers are called for in future sessions as well as possible countries/researchers to follow-up on individual components or possible collaborations to address specific issues.

**Evening Activities - on your own** 

# Wednesday, February 20, 2002

8:00 – 8:30 AM: Continental Breakfast

8:30 – 12:30 AM: Morning Sessions

Morning Chairperson: Don Lollar, Director, Office on Disability, National Center for Birth Defects and Developmental Disabilities, CDC, U.S.A.

# 8:30 – 9:00 AM: Session 10 - Discussion of Comparability of Information Cross-nationally

The group will be split into four discussion groups. Using materials condensed from the previous day, each group will discuss the major identified issues related to formats and forms of data collections. How well do the global indicators serve the purposes of various countries? The groups will also decide what they consider priority issues to be pursued by the city group and will discuss the global measures, identifying those which appear to satisfy the needs of the data collection process, including data comparability.

#### 9:00 – 10:30 AM: Breakout Groups Facilitators:

**Group 1:** Helen Nviiri, Uganda Diane Shinberg, USA

**Group 2:** Sam Notzon, USA Renee Langlois, Canada

**Group 3**: Jacques Bonte, Belgium Nora Groce, USA

**Group 4:** Genara Rivera Araujo, Peru (invited) Yiu-choi Siu, Hong Kong (invited)

10:30 - 10:45 AM: Break

# 10:45 – 11:30 AM: Total Group Discussion - Priorities

Groups reunite at midmorning to report their findings and discuss the nature of the most difficult differences. This would also provide an opportunity to develop further agenda items for subsequent meetings.

### 11:30 AM – 12:30 PM: Cross-cultural Validity of Global Indicators

Can we agree on what specific global indicator or set of global indicators is workable?

**Moderator: Jennifer Madans**, Associate Director for Science, National Center for Health Statistics, USA

12:30 – 1:45 PM: Lunch – On your own

# 1:45 – 3:30 PM: Afternoon Session

<u>Afternoon Chairperson</u>: Marleen De Smedt, Statistics on Health and Safety, Eurostat, EC

# 1:45 – 3:30 PM: Session 11 - Conclusion and Wrap up

Selection of Organizing Committee for next Meeting Selection of Site for next meeting Review of Next Steps recommendations/ possible products Development of assignments for next meeting