Final Report of First Meeting

WASHINGTON CITY GROUP ON DISABILITY STATISTICS

February 18-20, 2002

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Section 1: Background and organization

Meeting location
The first meeting of the Washington City Group on Disability Statistics, initiated by the United Nations and hosted by the National Center for Health Statistics of the Centers for Disease Control and Prevention, was held on February 18 - 20, 2002 at the Omni Shoreham Hotel in Washington, DC (USA).

Participation
The planning group for this meeting was comprised of representatives from Australia, Eurostat, Mexico, Uganda, and the United States. Representatives from the national statistical offices of 30 countries and one U.S. commonwealth participated in the meeting. Participating countries included Australia, Belgium, Brazil, Canada, Denmark, Egypt, Finland, France, Hong Kong (China), Hungary, Israel, Italy, Ivory Coast, Japan, Kenya, Luxembourg, Netherlands, Peru, Philippines, Poland, Puerto Rico, Sierra Leone, South Africa, Spain, Sweden, Tanzania, Uganda, United States, Vietnam, Zambia, and Zimbabwe. Eurostat participated in the meeting, representing European member nations. Representatives from the following organizations also participated: National Institute on Disability and Rehabilitation Research, African Rehabilitation Institute, European Disability Forum, Council for Disabled People-Mexico, World Health Organization, United Nations, and the Centers for Disease Control (U.S.). In total, 58 persons participated in the meeting.

Organization of Meeting
This meeting was organized to promote discussion and to develop agreement among the attending nations on the goals and products of the City Group. In order to attain the objectives, the sessions were organized around short specific presentations that identified important measurement issues followed by periods of discussions. The discussions were guided by the session Chairpersons who had developed questions to pose to the group concerning the specific issue addressed in the session. Attempts were then made to note the areas of agreement and to develop next steps for the City Group to consider in subsequent meetings. The papers presented at the various sessions can be viewed on the Washington City Group website: http://www.cdc.gov/nchs/citygroup.htm. The organization of this report identifies the session topics and documents the discussions which followed the presentations. It identifies the following components of each session discussion: Chairperson's questions; points of agreement; suggestions for next steps; and unresolved issues which were to be discussed in later sessions or future meetings.

Objectives
1) Recommend principles to guide development of global measures of disability, for use in a census format, which are culturally compatible and that will provide basic necessary information on disability throughout the world.

2) Recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components in population surveys or as supplements to specialty surveys. Such principles for developing questions should

be representative of the ICF model and culturally comparable. Modular components can be conceptualized such that they could be combined to encompass the body/structure, activity/participation and environmental components of disability where possible.

3) Address the methodological issues associated with measurement of disability considered most pressing by the participants.

In order to meet these objective it will be necessary to:

Review and assess cross cultural differences in disability definitions, purposes for collecting disability information and barriers to collection of accurate disability data as a step in promoting comparability and usefulness of disability data collected either by census or survey.

Review sets of global measures used in censuses and survey measures currently in use or proposed in participating nations, developing the underlying principles that indicate successful measurement.

Evaluate methodological problems in developing measures, particularly in the new areas of measurement of participation and environment as well as in measurement of special populations, in order to promote development of culturally compatible measures in these areas.

Continue building a network of institutions and experts, including producers and users of disability statistics, to implement the development in this field so that the data collection instruments will be put to use to produce information needed in this area.

Section 2: Account of proceedings

MONDAY
Opening Session - Introduction And Overview

Jennifer Madans (National Center for Health Statistics (NCHS) served as chairperson for the morning session. She opened the meeting by welcoming the group and thanking the Planning Group and financial supporters. Ed Sondik (NCHS) provided introductory comments and highlighted the importance of international comparison of disability measures. Hermann Habermann (United Nations) explained the history and purpose of City Groups and delineated their role relative to the United Nations (UN). He outlined the City Group's "challenge" for this meeting that included consensus on a manageable small set of objectives, designation of a secretariat for the next meeting, delineation of the agenda for the next meeting, and generation of a report to the UN Statistical Commission for their meeting in March of 2002. The UN role relative to the City Group included provision of modest support for developing countries to participate, representing views of

developing countries that cannot attend, and facilitation of outcomes. Jennifer Madans reviewed the organization of the meeting including objectives, the process to be utilized, and the anticipated products. She emphasized the importance of delineating the next steps that would be necessary to address issues raised after each group of sessions. She provided an opportunity to adjust the objectives. This was addressed again later in the morning session. Barbara Altman reviewed relevant aspects of the June 2001 UN seminar on disability measurement to insure continuity between the issues raised in the seminar and the work of the City Group. All City Group participants introduced themselves prior to further discussion of the morning presentations.

Points of discussion:
- Concern for special populations, such as children with disabilities.
- Concern about conceptual and methodological problems related to disability measurement. It was noted that the definition of disability might vary with purpose (i.e. civil rights versus resource allocation). Individual conceptualization of disability (disability identity) may affect information that respondents provide. In response, it was confirmed that these issues would be a primary focus of discussion for the meeting.

Areas of agreement:
- Consensus on need for and use of disability data that is internationally comparable.

Session 1 - Goal Setting and Agenda Adjustment

Jennifer Madans moderated the discussion. Objectives were reviewed and revised by the group. Working from the June seminar, the plan was for the emphasis of this first Washington City Group Meeting to be directed toward global measures, addressing cultural barriers to measurement and assuring some compatibility among measures that originate in different cultures. In addition, there would be explicit discussion regarding measurement of participation and environmental factors as related to global measures.

DISCUSSION

Questions from the Chair:

Are there additional objectives we want to address for this meeting?
Are there additions to the agenda that need to be considered?

Points of discussion:
- The term "global" was determined to be problematic due to differing interpretation of it's meaning. Concepts and candidate replacement terms for the phrase "global measures of disability" were:
  o Holistic
  o Comparative
  o Nationally and internationally comparable
  o Single measure
  o Comprehensive measure

- o Basic identifying question, identifier (of length and type as on a census)
- o All encompassing measure
- o Broad
- o Screener
- There was discussion that consideration of the limited resources of some countries is necessary. Some countries will have only one disability question on a census.
  - o A suggestion was raised to allow countries to choose one question from the short set of general disability measures.
  - o A question was raised whether a single question can provide the necessary information for the intended purpose. It was suggested that the limitations of use of a single question be delineated. Alternatively, if a single question is not adequate, justify why additional measures are needed.
  - o The point was raised that whether one question is suitable depends on the purpose of measurement.

Areas of agreement:
- Consensus was reached on the use of "comparable general disability measure" to replace "global measure".
- There was agreement on the need for both a single or short set of measures (indicators) that could be used on censuses or surveys and a more extensive set of measures (module) that could be used in health surveys and/or supplements.
- There was agreement that the long set of measures should be cross-walked back to the short set of measures (indicators).
- Agreement on the need to define disability (to identify concepts) and to describe what is to be measured was introduced as a meeting topic.
- There was consensus that an additional objective of the CG be the promotion of the regular generation of statistical information on disability by statistical offices around the world.

Unresolved issues:
- Defining / conceptualizing disability
- Determination of what is to be measured
  - o Measurement of performance versus capacity
- How to use the information about disability appropriately

Session 2 - Purpose of Measurement
Marijke de Kleijn-de Vrankrijker chaired the afternoon sessions. Roberta Crialesi from Italy, Eva Gardos from Hungary, Bothaina El Deeb from Egypt, and Alicia Bercovich from Brazil made presentations about the types of data and methods of data collection in their respective countries.

Preamble to the session from the chair:
The purpose of measurement could vary according to the level (country level, regional i.e. EU level and world level) and according to the policy area (i.e. employment, health and special disability policies, policy and planning of social care) for which data on disability are needed. Another purpose of disability measurement could be to examine

differences in disability between different regions, in particular with respect to environmental factors and socio-economic factors. What is the consequence of this for the required data in terms of the ICF?

DISCUSSION
<u>**Questions from the chair:**</u>
Who needs this information?
Why do we need this information?

<u>**Points of discussion:**</u>
- The purpose of data collection holds an important key to measurement
- The following list reflects groups needing disability statistics:
    - Researchers
    - Stakeholders / users
    - Public / citizens
    - Policy makers
    - Associations (NGOs)
    - Trade unions
    - Government agencies
    - International organizations
    - Health service organizations / providers
    - Industry
        - Device / equipment manufacturers
        - Employers
    - Consumer groups
    - Insurance agencies
    - Education planners
    - Media
    - Data users
- The following represent purposes for which data are collected:
    - Planning
    - Evaluation
    - Marketing
    - Policy development and evaluation / Political action
    - Advocacy
    - Prevention
    - Enhance participation
    - Improve services
    - Standard rules
- The group recognized that purposes might conflict with each other. Different countries may have different purposes for collecting data on disability. Multiple small sets of general questions may need to be developed and linked to the different purposes of measurement.
- The need for international comparison was discussed. International comparison is needed to:

- understand the disablement process;
- determine factors which impact on disability, i.e. major determinants of disability;
- compare effectiveness of policies / strategies used in different countries;
- affect the attitudes of society toward people with disabilities;
- identify differences or gaps (ethnic, age, regional gaps) in our understanding of disability (this is important if you try to understand the meaning of the gaps);
- understand how culture influences disability;
- understand impact of changing age structures in populations and how that relates to disability.

Areas of agreement:
- The CG will become familiar with the "UN standard rules".
- It was agreed that identifying the purpose of disability measurement and identifying cultural issues impacting measurement would assist in determining international comparability of measures.

Session 3 - An examination of the ICF Model
Session 4 - Discussion of the U.N. Standard Disability Tables Form, Principles and Recommendations for Population and Housing Censuses

Margie Schneider from the World Health Organization (WHO), Emmanuelle Cambois from Euro-Reves, and Niels Rasmussen Eurostat, made presentations on the ICF model in the first session. In the second session, Margaret Mbogoni and Angela Me from the UN made presentations discussing the multinational monitoring of disability data.

DISCUSSION
Questions from the Chair:

What part of the ICF do global measures pertain to?
What kinds of data are necessary for the purposes we discussed?

Is it necessary, in the light of the ICF, to revise the UN standard disability tables?
If yes, how could/should this revision be realized?
How could the implementation be monitored?
What practical implications will a possible revision have for the data collection and the delivery of data (to UN) for countries?

Points of discussion:
- The presentations identified the following issues to be considered:
  - Disability measures are not comparable due to validity issues. Measures lack reliability, conceptual framework, multi-dimensionality, and a holistic orientation.
  - We need to know how to translate complex concepts into everyday language to facilitate disability measurement.
  - We need to distinguish between performance and capacity.

- o Currently, there is limited use of the ICF model.
- o The concepts and definition of terms of the ICF are new to many countries.
- o There was concern about the accuracy of self-report given environmental factors, cultural factors, and stigmatization.

- Role of ICF as a framework for measures.
  - o Activity and performance; this is probably all you can measure in a survey context; participation has to be explored via multiple questions
  - o General questions/s should focus on activity limitation, but if people adapt their activities, you would miss them
  - o Let persons with disabilities define what is important in their lives; this is missing in the ICF
  - o Individuals would be missed by measuring only activity limitation; for example, if someone is HIV+, they might lose their job because of discrimination
  - o The UN provided their definition for classifying a person with a disability: "A person who is limited in the kinds or amount of activity that he/she can do because of ongoing difficulties due to a long term physical or mental condition or health problem." The UN is recommending questions about difficulty performing activities followed by questions about activity limitation. The UN is still recommending the activity limitation approach.
  - o Terminology such as "long-term", "disability", and "handicap" are perceived as negative and tend to lead to underreporting.
  - o Scaled responses help respondents to report disability.
- There was consensus that the UN should consider discussing recommendations for statistical data collection with the WCG.

Areas of agreement:
- ICF makes a good framework for measures, but has its limitations.
  - o Activity and performance is probably all you can measure in a survey context; participation has to be explored via multiple questions

Unresolved issues:
- Disability tables were designed with the ICIDH model (now the ICF). Group would like the UN to clarify any changes necessary.
- The number of general disability measures to be included in the small set of measures is unresolved (8 is too many).
- The dimension of the ICF that we will measure is unresolved at this point.

Tuesday
Session 5 - Global Measure of Disability

Richard Madden chaired the morning sessions. He began by summarizing the Monday afternoon session regarding who are the users (commentators, consumers, and service providers) and why they need the data (prevention, assistance, advocacy).

Joanne Hillermann presented a description of the Australian experience with disability questions on their census. The goal was to produce questions that were reliable, could be included in self-enumeration form, and were comparable to measures in their disability survey. However, they were unsuccessful in developing a measure of sufficient quality to use in the 2001 Census despite significant development and testing. Margaret Mbogoni presented a discussion of how country representatives reviewed the status of their ability to implement the recommendations of the U.N. for data collection on disability.

DISCUSSION

Points of discussion:
- What definition of disability was used?
- How was the issue of help addressed (needing versus receiving)? The problem with the help questions is that respondents may need help, but receive it only if it is available (dependent on living arrangements, resources).

Unresolved issues:
- The need for additional training on the ICF, and implementing the UN guidelines was identified by some developing countries.
- The need for clarification on how to address assistive device use was raised.
    - There needs to be consistency about incorporating device use or not.
    - Whom are we trying to capture? Do we want to capture those at risk for disability or those with limitation right now? The intersection is critical to the question you are going to ask.
    - What are we trying to measure? Measuring how many can see with glasses addresses the issue of unmet need.
- How to deal with the issue of space limitations on censuses.
- Need for a severity measure.
- Request for advice from developing countries undertaking census now.
- The difficulty that statisticians have in influencing census questions.

Session 6 - What is the Relationship of Global Measures to the ICF?
Session 7 - Exploring the Confounding Function of Assistive Device Use

Presentations which examined the relationship of the ICF and global measures were given by Renee Langlois who described the PALS questions used in the Canadian census, and Joanne Hillermann who described the mapping of the Australian disability survey and module to the ICF. This was followed by a presentation by Jennifer Madans which

examined the use of assistive devices by respondents and how such use may mask accurate identification of persons with disabilities.

The objectives of global indicators in the Canadian and Australian studies were described. Precision is needed to provide broad information on specific characteristics in the population while inclusiveness is needed when screening for follow-up in a subsequent survey. The Canadian census module is used to screen the population for the PALS follow-up survey. The screener question in the Canadian census included: linkage to a long-term health condition (>6 months), applicability to the entire household population, brevity, clarity of language, intuitiveness to respondents, and inclusiveness of all levels of severity. Efforts were made to avoid non-reporting caused by use of negative language and restrictive response categories. The Canadian measure/s focus on the activity limitation / participation dimension of the ICF.

The Australian experience with a disability module, a census module and a disability survey were described. The population with disability was identified via screener questions. The ICF domains of body function, activity limitation, and environment were measured in the survey and module, but only body function and activity limitation were captured in the census.

Data from the U.S. demonstrated the effects of assistive device use on prevalence estimates of disability. It was shown that there are individuals using assistive devices that do not report limitations and, therefore, would not be captured by in surveys that define disability based on reported limitations and do not include questions about assistive device use.

DISCUSSION
Questions from the Chair:
       Is there consensus that a census measure of disability is feasible? (Summarize broad cost/benefit issues: identify additional work on these)
       Is there agreement that a "standard" census measure of disability is possible? If so, how much consistency in actual wording is desirable or feasible?
       Should a standard measure cover all disability or a more limited group, such as those in need of assistance?
       What are the ICF components / dimensions on which such a measure should be based? Should a common international minimum set be sought? Lessons from DISTAB?
       What is the consistency or relatability between census and survey estimates?
       Is there a need to be specific about assistance? Are some domains more important / easier, e.g., vision? What are the social issues involved? Are ICF qualifiers adequate?

Areas of agreement:
- Consensus that a census measure is feasible
  - Mapping to the ICF is only a consideration.
  - There needs to be specificity about the purpose and limits on the objective.
  - It would be best to measure activity since it is easier to measure and will be more comparable.

- o Resources of country should be taken into consideration
- Plan research agenda around testing candidate questions in developing countries.
- Terminology should be internationally, culturally comparable.
- There was a recognized need for training, technical support, and collaboration
  - o UN should provide additional technical assistance and training to developing countries.
  - o Recommendation that networks be established in the context of the CG so that countries could partner with each other for guidance and technical support.

Unresolved issues:
- There was a comment that the use of assistive devices is very different internationally and this might interfere with comparability of disability measures.
- Issues related to duration and severity of disability, and whether to measure capacity vs. performance
- Consideration should be made for countries with a need for impairment data only.

Session 8 -   What are the Unique Cultural Practices that Influence the Nature of the Environment or Prescribe or proscribe Participation?

Nayiga Ssekabira chaired the afternoon sessions.

Margie Schneider and Nora Groce addressed important cultural issues that influence how disability is seen in various national groups and also identified possible circumstances that would influence the collection of disability data differently in different cultures.

Issues raised for consideration included the need for culturally relevant assessment tools, the fact that cultural norms determine whether participation is relevant, that cultural practices may themselves contribute to impairment of individuals within the society, that cultural beliefs may interfere with accurate responses to questions about disability (due to fear, stigmatization, marking, gossip), and that language issues may compound difficulties with comparability of measurements (in some countries there is no word for disability). It was noted that disability is not static. It was emphasized that clarifying the purpose of measurement will determine, in part, whether cultural issues related to comparability are surmountable. It was also emphasized that people with disabilities must be a part of the questionnaire planning process.

DISCUSSION
Questions from the Chair:
> *Are cultural differences so imbedded in the definition / conceptualization of disability that international comparisons are impossible?*
> *Are there areas where comparisons are possible?*
> *Are there ways to obscure differences?*
> *How do we test for comparability?*
> *Based on the World Health Organization's experience, what have we learned about how cultural issues affect the measurement of environmental factors?*

What are the key cultural issues in your society related to disability measurement?

Points of discussion:
- There is the issue of a high proportion of illiteracy among people with disabilities in some countries; it is difficult to get around the stigmatization problem
- How social inequality impacts measurement
- In some countries there is family protection of persons with disability, sometimes the person is hidden from society
- It is difficult to get accurate information about mental health because of cultural issues
- Disability is defined differently in different countries…in Scandinavia, severe allergy is considered a disability
- There is a misconception that persons with disabilities need to be helped, that they are not self-reliant
- In some countries, infants born with disabilities are killed before being named, so there is a low prevalence of severe disability in these countries
- The census is an important way that new ideas come into a country

Areas of agreement:
- Self-representation of persons with disabilities is important.
- People (respondents) do not know the difference between disability and impairment. People from different countries interpret the concept of disability differently
- It is important to implement awareness raising programs before a survey or census to educate and prepare potential respondents
- We need a clear definition / conceptualization of disability.

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?

Hermann Van Oyen discussed the difficulties translating concepts from one language to another and proposed a solution to this problem.

The EU experience related to cultural issues when measuring disability was presented. There was an emphasis on the need for agreement among CG participants about the concept of disability in order to facilitate comparability (agree on what to measure, for whom and why). The point was made that questions need to be intuitive for the respondent. The proposed methodological approach called for conceptual description, reference standard instruments, and operational standard instruments as inputs and statistical tools (response conversion techniques) as the output.

DISCUSSION
Questions from the Chair:
Do we feel there are important cultural issues to consider when developing guidelines for global measures of disability?

Points of discussion:
- Difficulty obtaining mental health data
- Political influence on data
- Multiple language translation necessary for many countries

Areas of agreement:
- Cultural issues should be resolved at the country level; the CG guidelines should make a recommendation that countries be aware of unique cultural issues that might influence comparability of data on disability
- We need a clear definition / conceptualization of disability.
- We will need to be able to translate survey terminology related to disability conceptually rather than literally; we should include translation and back-translation of the terminology to be sure that we have captured the appropriate concepts related to disability
- Persons with disabilities should be included in the questionnaire development process

Wednesday
Session 10 – Discussion of Comparability of Information Cross-nationally (break-out group session)

This session was chaired by Donald Lollar. Following the distribution of instructions, the participants broke into 4 separate groups and worked on arriving at agreement on important issues, and next steps. Instructions to the groups, handouts, and summaries of group discussions can be found in Section 4 of this report (Appendix). At the conclusion of the group meetings, Don Lollar summarized the group reports.

Agreements:
- There is agreement that the purposes of measurement are for identification (of persons with disability), planning / description, and to provide information for publicity/media.
- Duration, type and severity of disability should be addressed by the measures
- Measures should move from general to specific (such as examples 3 and 5 in the question typology, but we are not ready to adopt these as interim measures yet)
- Measures should be based on activity
- Countries will have autonomy regarding translation of question such that the concept of the question is captured accurately

Unresolved issues
- We have not agreed on the utility of the ICF as a framework; we need to "buy in" to what dimension we will be measuring in order to have comparability
- Whether and how to capture the environment / participation dimension
- We need field work to determine problems with using measures in different countries

- Need to determine why some countries want to measure body structure/function dimension so we can make a decision about whether to incorporate it in our general measures

Wednesday – Last Session
Session 11: Conclusion and wrap-up
Marleen De Smedt chaired the afternoon session. Five topics were discussed.

1.   Accomplishment of the objectives of this meeting
2.   Areas of agreement
3.   Message to Statistical Commission
4.   Dissemination
5.   Next Steps (practical issues for the next meeting)

Outcomes from this session are presented in Section 3 of this document.

Section 3: Conclusions, Recommendations and Next Steps

Revised Objectives
The objectives were revised and accepted by the group. The revised objectives are:

1. To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world.

2. To recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items will be related to the general measures.

    Measures identified in objectives 1 and 2 will be culturally comparable to the extent possible. The ICF model, a useful framework to assist in the development of these measures, will be utilized in developing the measures.

3. To address the methodological issues associated with the measurement of disability considered most pressing by the City Group participants.

Final Areas of Agreement
The participants were in general agreement about the majority of the areas discussed. As one of the concluding activities of the meeting, participants reviewed a summary of the meeting and endorsed the following points:

Purposes of objectives:

To promote regular collection and generation of statistical information on disability by statistical offices in populations around the world.

To assist countries in justifying the collection of disability information on censuses and within statistical systems in light of limited resources and competing demands regarding issues of national importance.

To understand the role of statistical systems in providing information to policy-makers about disability in their efforts to promote full participation and improve quality of life among people with disabilities.

Points of agreement:

1. It is important and possible to craft internationally comparable general disability measures. Comparable general disability measure (or question) is a term to be used in place of the term "global measure" to reduce confusion about multiple meanings of the term "global".

2. Given that there are multiple purposes for the use of a general disability measure, it may be necessary to develop multiple internationally comparable general measures relevant for several specific purposes.

3. A short set of measures should be developed for use in censuses and surveys. And a longer set of measures (questions) should be cross-walked back to the short set of indicators.

4. The agreed-upon minimum requirements for such a measure would be:
   A clear link of the purpose of measurement to the operationalization of the indicator(s);

   A clear and specific definition of the aspect of "disability" to be measured;

   Flexibility in translating an agreed upon reference document (that clearly outlines the concepts to be used, question wording, and response categories) into multiple languages to allow the use of the appropriate terminology in each country;

   A specification of the limitations of the general measures;

   A specification of how personal assistance or device use is treated in relation to the measure.

5. An initial focus for an internationally comparable general indicator should be the activity dimension of the ICF.

6. The Washington City Group should be concerned with:
   The provision of technical support for the development of internationally comparable general measure(s); and
   A research and testing program for indicator development

7. Census and survey questions for the indicators should avoid words with a negative connotation such as "disability."

8. Persons with disabilities should be included in the development of indicators.

9. The development of working networks among participants and of a process through which technical assistance can be provided to countries with fewer resources is a high priority for an outcome of these meetings.

10. A product of the first meeting of the Washington City Group is a prioritized list of issues to be addressed at future meetings.

Message to the Statistical Commission
Jennifer Madans will report the following information to the UN Statistical Commission:
Revised Objectives
Areas of Agreement
Dissemination of the Results of the First Meeting
Next Steps

Dissemination of Results of Meeting 1
It was agreed that the results of the first Washington City Group meeting would be disseminated by several methods. The current chairperson of the planning group, Jennifer Madans, will present a short report to the United Nations Statistical Commission. That will be followed by a full report of the meeting that will be sent to all participating countries. The full report will also be posted on to the website, and provided to all the venues to which City Group materials are customarily distributed. Additionally, all presentations given at the meeting will be made available on the website. Finally, materials from the Washington City Group will be published in a special issue of *Research in Social Science and Disability*, a peer reviewed journal published by Elsevier publishers. The materials that will be included in this hardcover publication consist of a selection of papers based on presentations from the initial United Nations Seminar on Measurement of Disability, papers based on presentations at the first meeting of the Washington City Group and the City Group extended report.

Next Steps – Planning for Future Meetings
A proposal was made for the second meeting of the Washington City Group to be held in Europe, in recognition of the European Year of People with Disabilities (2003). The feasibility of that venue will be known in about two months.

The first objective in the second meeting of the Washington City Group is to provide a recommendation for a set of comparable general disability measures that can be used for various purposes. In order to accomplish that objective the following work needs to be accomplished:

Completion of a matrix developed and agreed upon at the first meeting that matches the purpose of the proposed general measure(s) (question) with conceptual definitions, items, reference questions and characteristics of questions including such aspects as whether duration is an important element of the question;

An evaluation of measures currently in use according to the dimensions of the matrix;

A review of the results of methodological testing of general measures that has been done in various countries including Canada, Australia and Eurostat;

If possible, one or two of the candidate general measures should be tested in several countries, particularly in developing countries, with results reported to the next meeting.

The second objective of the second meeting would be to begin exploration and discussion of sets of measures, related to the general measures, to be used as components in surveys. Questions addressing environmental factors and participation were of particular concern for exploration and discussion for another set of questions.

A third objective of the second meeting is to focus on methodological issues. Two areas under consideration are special populations, in particular collection of data associated with mental health problems, and use of administrative data alone or in conjunction with survey or census data.

It was estimated that an additional three meetings would be needed to complete the work plan. It was also suggested that at each meeting there is a need for assessing progress and making decisions if continued work is necessary on any topic.

Planning Group for Second Meeting of Washington City Group

Participants of the meeting were invited to join the planning group for the second meeting of the Washington Group, or to volunteer to take responsibility for one of the items to be addressed in the second meeting. A meeting of the planning group took place following the conclusion of the first Washington City Group Meeting. The planning group consists of members from the following countries or cooperative groups: Australia, Belgium, Brazil, Canada, Eurostat, Hungary, Italy, Netherlands, Poland, Uganda and the United States. Involvement of some countries mentioned here is subject to agreement of the national authorities concerned.

Section 4: Appendix

This appendix contains instructions, handouts, and discussions from the four breakout group meetings.

The first matter of business was presentation of the "Areas of Agreement" summarizing consensus items and unresolved issues from the first two days of the meeting. Breakout groups were given the following instructions:

✓ Groups should discuss the purposes for which an internationally comparable general disability indicator [global measure] could be used.
✓ Groups should consider the types of questions that have been used already (and might be used as interim questions in the short run) for an internationally comparable general disability indicator.
✓ Groups should consider the characteristics of questions associated with or appropriate for specific purposes.
✓ A summary of points of perceived consensus reached during the first two days of the meeting was provided. Each group should review this document.
✓ The last ten minutes of the discussion in each group should be reserved for consideration of next steps.

Three documents were distributed and are provided here: Purpose of Disability Measurement, Question Typology, and Areas of Agreement. Each group reviewed the documents, discussed the items, and reported back to the full group.

Handout #1:
Purpose of Disability Measurement

Purpose: Who needs this information?

Policy Makers / Decision Makers	Parliament Ministers of Health, etc.
Administration	International National Education planners
Industry	Employers Insurance companies Producers of technical aids and consumer goods
Care delivery	Service providers
Research	Researchers
Consumers	Organizations Self advocates
General public	Citizens Media

Purpose: Why do they need this information?

Purpose / why	Usefulness of a global indicator		
	+ Yes, useful	+/- Yes, only as a first indicator	- Not useful
Planning		X	
Political action	X		
Advocacy	X		
Marketing			X
Prevention			X
Enhance participation / QOL	X		
Improve services		X	
Evaluation		X	
Standard rules	X		

Question Matrix

Purpose of measurement linked with question characteristics

Purpose of Global Measure	ICF Domains	Capacity/ Performance	Duration	Dichotomous/ Multiple	Severity	Assistive Devices
Service Provision						
Policy						
Public Health						

KEY

ICF Domains: Which domain should be used for the measurement depending on purpose?

Capacity/Performance: Does the purpose require measurement of performance or will capacity better inform the question purpose?

Duration: Is it necessary to identify that the problem is of long term duration?

Dichotomous/Multiple category answers: Is a yes/no response sufficient or will multiple categories provide more needed information?

Severity: Are levels or severity necessary to the purpose or is a broad measure the most suited to the purpose of the question?

Assistive Devices: Do we want to know about persons using devices who do not necessarily report activity or participation limits?

Handout #2: Question Typology *(Based on general disability questions in use)*

1. **Impairment Identification** - This type of questions asks about the presence of an impairment based on different parts of the body system.
   1A. Impairment Identification and Cause – Impairment identification is accompanied by second question that seeks cause of impairment.
   Example: Have you been diagnosed by medical specialist

2. **Identification of a Disability** – This type of question asks directly if the person is disabled, in some cases is followed by a question identifying the disability in terms of functional limitations.
   Example: Does –have a disability? Yes/No
   If yes, type of disability
   1. Difficulty moving/physical disabilities
   2. Difficulty seeing
   3. Difficulty hearing/speaking
   4. Difficulty learning/mental handicap
   5. Chronic fits
   6. Strange behavior/mental illness
   7. Difficulty feeling in hands or feet/leprosy
   8. Albinism
   9. Multiple difficulties that are a combination of the above.

3. **Indication of limitations in any activity** - This type of question just asks about limitation of activity without definition of activity.
   Example: Are you limited in any activities because of physical, mental, or emotional problems?

   Yes / no / don't know, not sure / refused

4. **Indication of Difficulties** – This type of measure identifies whether respondent has difficulties.
   Example:
   a. How much difficulty does the person have in doing everyday activities such as eating showering or dressing?
   b. Hearing?
   c. Learning, understanding or remembering?
   d. Reading or seeing even with glasses?
   e. Walking, kneeling or climbing stairs?
   f. Living independently?
   g. Doing any other things people of the same age usually do (for example, working, studying, etc.)
   None / a little / a lot

5. **Combination questions:**
   A. Health in general, chronic condition and limitation in activities
   B. Conditions, need for help or supervision, or difficulties
   C. Difficulty with functioning, reduced amount or kind of activity
   Example: Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
   Yes, sometimes / Yes, often / No

Handout #3: Areas of agreement

<u>Preamble</u>

To promote regular collection and generation of statistical information on disability in populations by statistical offices around the world

To assist countries in justifying the collection of disability information on censuses and within statistical systems in light of limited resources and competing demands regarding issues of national importance

To understand the role of statistical systems in providing information to policy-makers about disability in their efforts to promote full participation and improve quality of life among people with disabilities

<u>Areas of agreement</u>

It is possible to craft internationally comparable general disability indicator(s). [global measure]

The agreed-upon minimum requirements for such an indicator would be:
   A clear link of the purpose of measurement to the operationalization of the indicator(s)
   A clear and specific definition of the aspect of "disability" to be measured
   An appropriate terminology in multiple languages
   A specification of the limitations of the indicator(s)
   A specification of how personal assistance or device use is treated

An initial focus for an internationally comparable general indicator should be the activity dimension of the ICF.

The Washington City Group should be concerned with:
   The provision of technical support for the development of internationally comparable general indicator
   A research and testing program for indicator development

Given that there are multiple purposes it will be necessary to develop internationally comparable general indicators relevant for each specific purpose.

A short set of indicators should be developed for use in censuses and surveys. And a longer set of indicators should be cross-walked back to a short set of indicators.

Census and survey questions for the indicators should not specifically include the word "disability."

Persons with disabilities should be included in the development of indicators.

A product of the first meeting of the Washington City Group is a prioritized list of issues to be addressed at future meetings.

Unresolved issues

Cultural comparability issues	Definition of disability (and alternative terms)
Mental health	Severity, duration and subtypes of disability
Devices, aids & assistance	Measurement characteristics of indicators
Special populations	

Break-out Group Discussion Summaries

Summary of Group 1

Purposes:
- Resource allocation / planning
- Prevention / public health intervention

Types of questions that could be used as a general disability indicator:
- Focused on activity (like #5 in the question typology) or more generic (like #3 in the question typology)
- An international approach needs to be at the generic level because of cultural issues and translation
- Conceptually comparable
- Would like the option of more detailed questions that could be related back to the general question/s
- Some countries need impairment measures (i.e. on blindness) for specific purposes
- Orient the questions toward activity / participation

Agreements:
- This group agrees with the "Areas of Agreement" document, although notes that use of culturally compatible terminology will be difficult to achieve

Unresolved issues:
- How and whether to capture duration and severity of disability
- How and whether to capture assistive device use
- How and whether to capture environment dimension

Next steps:
- Technical comparability of methods
  - Cultural / language comparability
  - What are we measuring (define disability conceptually)
  - Comparability of short and long sets of questions
- ICF dimensions
  - Activity limitation focus, but how do we handle impairments (body structure/function)?
- Development of research and testing program for question development

Summary of Group 2

Purposes:
- The purposes for identifying persons with disability in a population exist on a continuum from planning to programming to evaluation

Types of questions that could be used as a general disability indicator:

- There was no agreement on the type of general disability indicator (because it depends upon the purpose of measurement), only on characteristics of disability indicators (described below)

Agreements:
- This group agrees with the "Areas of Agreement" document with the following clarifications:
  - It was emphasized that not only is it possible, but important, to craft internationally comparable general disability measures
  - Not all of the minimum requirements for general disability measures were discussed; there was not agreement about the need to measure device use
  - It was emphasized that the Washington CG should be concerned with the provision of technical support and encouragement for the development of internationally comparable general indicators
  - Clarified the statement "Given that there are multiple purposes, it may be necessary to develop internationally comparable general indicators relevant for each specific purpose"
  - Questions should avoid terms with negative connotations
- Characteristics of general disability measures should include:
  - Measurement of activity limitation, if followed by questions on functional limitation
  - Disability duration should be > 6 months
  - Response scales with multiple options should be used
  - It is important to measure severity of disability

Unresolved issues:
- Measurement of health versus disability
  - How to treat health conditions which result in participation restrictions
- How to handle assistive device use
- Type of general disability indicator
- Measurement of participation and environment
- Measurement of multiple disabilities
- Methodological issues such as homelessness, comparability of data from different sources, and cascading indicators

Next steps:
- Same next steps as Group 1
- Special populations (mental health, mental retardation)
- Additional unresolved issues
  - Consideration of health versus disability
  - Issue of multiple disabilities
  - Special health problems (HIV, Alzheimer's)
- Encourage countries to include testing / evaluation of disability questions

Summary of Group 3

Purposes:
- Descriptive / planning / programmatic development
  - Questions must be useful at national level if they are to be useful at international level

- Activity / participation dimension should be measured, but decision should be at country level whether to measure activity or participation; since activities that people do around the world are totally different so the greater need may be to measure participation
- It is not of interest to this group for the purpose of international comparability to rank countries, rather, it is of interest to individual countries to obtain information about disability for internal planning purposes

Types of questions that could be used as a general disability indicator:
- There was no agreement on the type of general disability indicator, only on characteristics of disability indicators (described below)
- Some combination of #3 and #5 in the question typology, moving from generic to more specific, were considered as possibilities with specification about duration and severity of disability
- If the purpose is for description / planning then the type, nature, and severity of the disability needs to be captured
- Need to clarify for whom the data are being collected; this dictates the level of detail and purpose; if data are being collected for policy makers they can be general; if they are being collected for care planners they need to be more specific
- Need to clarify disability definition (concept)
- Characteristics of general disability measures should include:
  - Scaled
  - Applicable to all groups within a population (age, gender, ethnicity)
  - Comprehensive
  - Address type, severity, duration of disability and need for assistance (technical or personal)
  - Use a menu system, cascading from generic to domain specific to type specific; initial question must be basic including identification of the problem and gradation (scaling)

Agreements:
- There is a need for a small set of comprehensive disability indicators for programming and policy purposes
- CG should be concerned with facilitating networking, communication, and accessing technical resources (with UN acting as secretariat / point of contact)

Unresolved issues:
- Countries need more information about the ICF; request for technical support in this regard
- Need conceptual definition of disability
- The type of general indicator has not been resolved

Next steps:
- Practical discussion of implementing this process in countries
- Decide on the timing of data collection (e.g. annual, decennial) and discuss other data collection issues
- Clarify the role between the UN and CG for collection of disability data
- Explore ways to have further research / methodological development on environmental issues

- Develop system for provision of technical assistance to countries regarding data collection methods
- Develop system for CG to facilitate technical network (with UN as point of contact)
- Ask countries to identify limitations they have for doing this work (homework for next meeting). What are the issues for implementation in individual countries?

Summary of Group 4
Purposes:
- Policy, planning, administration
- Descriptive (describe population)
- Political advocacy if combined with other information on disability (to take place at the national level, not the global level)
- Can use general measures as a reference if placed in other surveys (in addition to census)

Types of questions that could be used as a general disability indicator:
- Taxonomy was viewed as an excellent way to link the purposes of measurement with question characteristics. It was suggested to add two columns to the taxonomy table to designate a question as appropriate for census or survey, and to specify the recommended frequency of data collection for each purpose
- Groups such as the Canadians and Euro-Reves have a lot of experience with the measurement of the duration and severity of disability and with incorporating assistive device use into their measures. The WCG should consider these experiences when choosing / developing general indicators.

Agreements:
- At least 2 global indicators need to be established
- The plan for implementing comparable general measures should allow adaptation to specific needs of each country
- Negative terminology should be avoided; terminology must be culturally relevant

Unresolved issues:
- Issues of measuring duration, severity of disability and determining comparability of disability measures
- Issues related to measuring environment
- We still need to agree on the conceptual definition of disability, coding, and individual questions

Next steps:
- The next step in attempting to postulate global indicators is to summarize information into a new structure and review existing questions as possible candidates
- There is an urgent need to provide countries with a proposal of different general indicators that could be used for different purposes
- Address mental health
- Develop network to test candidate questions; questions need to be evaluated nationally before international comparisons can be made
- Address methodological aspects about measuring severity of disability, etc.