Washington City Group on Disability Statistics

Summary Report on First Meeting, February 18-20, 2002

Introduction

The first meeting of the Washington City Group, hosted by the National Center for Health Statistics of the United States, was held February 18 to 20, 2002 at the Omni Shoreham Hotel in Washington, DC. In addition to the host country, thirty-one countries sent at least one representative. Eurostat, coordinating the European Statistical System (ESS), WHO-HQ (Geneva) and International Organizations of people with disabilities were also represented. In total, approximately 64 persons participated in three days of sessions directed toward developing agreement on the nature of a global measure of disability to be recommended for use in censuses and surveys in the world community. The group also sought to develop an agenda for future meetings by prioritizing the most pressing issues in disability measurement and data collection.

The Washington City Group, which was established by the United Nations to enable the international community to address the themes and suggestions of the United National International Seminar on the Measurement of Disability, reaffirmed the need for a City Group to:

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

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

Understand the role of statistical systems in providing information about disability to policy-makers who are engaged in promoting full participation and improving the quality of life among people with disabilities.

Objectives

As the first order of business, the Washington City Group examined the objectives established by the planning committee. At the completion of the sessions and discussions, the group revisited the objectives and refined the wording to better represent the conclusions that had been reached. The following objectives were accepted enthusiastically by the participants and were used to guide the development of a work plan:

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.

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 minutes and endorsed the following points:

- 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.

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 the 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.