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**WASHINGTON GROUP (WG) ON DISABILITY STATISTICS:
AIMING AT CROSS-NATIONAL COMPARABILITY OF DISABILITY DATA**

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ABSTRACT

Because of the need for cross-national comparable disability data the UN authorized a City Group, the Washington Group (WG) on Disability Statistics, in order to make considerable progress in this area. The WG aims at the development of a small general disability measure (for censuses and sample based surveys) and a related extended set(s) of survey items (for population surveys or specialty surveys). Methodological issues related to both measures should be addressed as well. The paper describes objectives, working methods, progress made since the start of the work and expected results in the near future. Participants are invited to contribute good suggestions and comments concerning the development of the measures and the implementation of the results.

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INTRODUCTION

For several decades attempts have been made to improve comparability of disability data at the national and international level. In the early eighties of the last century the OECD published a short term time based and a long term function based disability indicator (1). The indicator was prepared by a committee of international experts (from Canada, Finland, France, Germany, the Netherlands, Switzerland, the United Kingdom and the United States of America). The Council of Europe and WHO-EURO promoted the indicator for the use in surveys in European countries with some deletions and additions (2, 3). Outside Europe the interest in using the indicator was very minimal.

The UN published guidelines for the development of disability statistics (4) referring to the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (5) and its successor the International Classification of Functioning, Disability and Health (ICF) (6). The publication includes recommended items to be measured in surveys without a special measure to be used. Work of the UN Statistics Division aims at improving the international comparability by promoting methods and use of international standards and includes regional training workshops (7).

The world wide interest in cross national comparability of disability data in terms of measurement agreement continued to remain. For this reason the United Nations International Seminar on Measurement of Disability took place in New York in June 2001 (8). An outcome of that meeting was the recognition that statistical and methodological work was needed at an international level in order to facilitate the comparison of data on disability cross-nationally. Consequently, the United Nations Statistics Division (UNSD) authorized the formation of a City Group to address some of the issues identified in the International Seminar and invited the National Center for Health Statistics (NCHS) to host the first meeting of the group. The City Group format is one that has been used by the United Nations (UN) in numerous other occasions to address various problems in survey measurement and methodology. A City Group is an informal, temporary, organizational format that allows representatives from national statistical authorities to come together to address selected problems in statistical methods. A City Group usually develops a series of three to four working meetings and is named after the location of the first meeting. Because the first meeting of this City Group took place in the city of Washington, its name became to be the Washington Group on Disability Statistics (WG).

OBJECTIVES OF THE WG ON DISABILITY STATISTICS

The WG, designated by the United Nations Statistical Commission, is an informal, consultative group of experts around the world, most of them being representatives from national statistical authorities and representatives of international organizations. The main purpose of the group is to agree on reference instruments for measuring disability in censuses and population based surveys in order to facilitate comparison of disability data cross-nationally.

The workplan of the WG is guided by the following main objectives, as they were reaffirmed during the first meeting (Washington, February 2002):

1. To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based 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.
3. To address the methodological issues associated with the measurement of disability considered most pressing by WG participants.

Measures identified in objectives 1 and 2 will be made as culturally comparable as possible. The International Classification of Functioning, Disability and Health (ICF) (6) model will be the framework in which these measures will be developed.

WORKING METHODS AND ORGANIZATIONAL ISSUES

The group meets at an annual base in different countries/regions (Washington February 2002, Ottawa January 2003, Brussels February 2004, next meeting in Bangkok September 2004). Participants are experts from statistical authorities from all over the world and representatives of international organizations who can take an active role (preferably one representative per country). Meetings are organized around papers prepared by individuals or workgroups. Meeting papers and reports are available through the website (9). The WG has to report annually to the United Nations Statistical Commission by a short report, see as an example the executive summary of the meeting in Brussels (see the WG website (9), third meeting document WG3.23).

In order to improve the processes a governance plan was adopted during the third meeting. The plan includes issues such as: membership, operating principles, organizational structure. A steering committee is elected with a chair and secretariat.

Objective 1: general measure

One of the results of the activities carried out by group members was the development of a matrix that cross-classifies the purpose that a general disability measure is supposed to address with a typology of question characteristics needed to achieve this purpose. Furthermore a lot of effort was put into developing an empirical version of the matrix to evaluate the characteristics of the general measures currently in use according to the dimensions of the matrix. These two matrices have helped to identify the gaps that exist in disability measurement and to direct future work in developing internationally comparable general measures of disability. Based on the disability matrix a position paper was prepared in order to select 1 or 2 purposes that the general disability measure should address. The paper took into account the rationale for the choice based on the relevance with respect to policy and feasibility of implementation with special attention to internationally comparability of disability data.

The three major goals of the World Programme of Action were presented as the possible purposes for the use of disability data:

1. provision of services,
2. monitoring the level of functioning in the population and

3. assessing equalization of opportunity.

Each of them was evaluated in terms of relevance and feasibility in the paper. Based on the discussions (second meeting) it was decided to give the highest priority to purpose 3, equalization of opportunity, as the purpose for internationally comparable general disability measure. Simultaneously the group prefers to work on purpose 2, monitoring the level of functioning in the population.

A workgroup was designated to generate a draft set of questions related to this purpose (short form) to be completed by the summer of 2004. This work should include: development of a list of measurement domains and criteria to rank domains for potential inclusion, determining if inclusion of a severity indicator is necessary, addressing the issues of accommodations (environment, technical aids). If time allows the group will pilot proposed questions.

A second workgroup will prepare a paper for the next meeting (September 2004) proposing methods for implementing the general disability measure (short form). This includes issues such as: pilot testing, data quality issues, translation, training and comparability issues after data collection.

Objective 2: extended sets

In order to make progress in the work relating to the extended measurement sets a third workgroup will prepare a paper proposing an approach for the development of extended measurement set/s related to the general disability measure/s. The paper will be discussed during the next meeting (September 2004).

The paper will include issues such as: purpose, relationship general and extended, required characteristics, existing and recommended items/questions to be taken into account, how to involve persons with disability in the development and in implementation of the instrument/s, methodological issues, implementation issues.

Objective 3: methodological issues

"Population coverage" is the methodological topic on the agenda for the next (fourth) meeting. Discussions based on presented papers will include:

- how to collect disability data among children
- and institutionalized population.

The aim of the discussions is to reach international agreement about the ways, how to do this.

A decision should be made which general methodological topics will be on the agenda for the future meeting:

- other issues related to population coverage (such as disability data on homeless people, foreigners and mentally ill persons),
- how to combine the use of administrative data and survey data,
- or other general methodological issues to be identified.

Expected results

As a result of the work by the WG we expect to present in the near future:

- a short general disability measure as a reference instrument (2004),
- a set of expended disability measures as reference instruments (2005),
- related to selected purposes and the ICF as the framework,

- with recommended solutions for important methodological issues associated with disability measurement (2004/2005),
- and recommendations for implementation of the recommended measures.

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Related European activities

- Eurostat
- Participation in WG work by EU member states
- Collaboration between EU member states for the WG work

REFERENCES

1. McWhinnie, J. R. Measuring disability, the OECD social indicator development programme, special study no 5. Organization for Economic Cooperation and Development OECD), Paris 1982.
2. Council of Europe. The use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in surveys and health-related statistics. Council of Europe, Strassbourg, 1990.
3. Bruin A. de, H. S. J. Picavet and A. Nossikov (ed). Health Interview surveys, towards international harmonization of methods and instruments. WHO Regional Publications, European Series, No. 58. Copenhagen, 1996.
4. Guidelines and principles for the development of disability statistics, United Nations, New York, 2001. ST/ESA/STAT/SER.Y/10
5. WHO, International Classification of Impairments, Disabilities and Handicaps (ICIDH), Geneva, 1980
6. WHO, International Classification of Functioning, Disability and Health (ICF), Geneva 2002
7. Mbogoni, M. On the application of the ICIDH and ICF in developing countries: evidence from the United Nations Disability Statistics Database (DISTAT). Disability & Rehabilitation 25 (2003) 644 - 658.
8. See for summarized results from the New York seminar: Background information at website www.cdc.gov/nchs/citygroup/htm
9. See the website of the Washington Group on Disability Statistics: www.cdc.gov/nchs/citygroup/htm