

REPORT OF THE FIRST REGIONAL MEETING OF THE WASHINGTON GROUP  
ON DISABILITY STATISTICS  
JUNE 20-22, 2005  
NAIROBI, KENYA

### **Purpose**

The main purpose of this meeting was the promotion of a small set of questions on disability (suitable for censuses) that can be used in many countries around the world. The aim is to use the data obtained from using these questions to produce comparable statistics on disability. A series of pre-tests of the core set of disability questions developed by the Washington Group (WG) is to be conducted in an attempt to arrive at a final set of questions. The purposes of this workshop are to: bring together persons representing countries interested in adding disability measures to censuses or improving measures already in place; familiarize countries with the goals of the WG; introduce the general measure designed by the WG and the rationale; encourage pre-testing of questions and provide the materials and training to facilitate pre-testing; develop connections between countries in the region to further facilitate the testing process; and to get feedback from countries on the question set as well as country specific conditions that need to be considered by the WG.

### **Participants**

Fifteen representatives from the national statistical offices of 13 countries participated in the workshop along with one representative of an international disability organization and 7 presenters. Country representatives included the Democratic Republic of Congo, Gambia, Lesotho, Malawi, Mauritius, Seychelles, Sierra Leone, Sudan, South Africa, Tanzania, Uganda, Zimbabwe, and the host country, Kenya.

### **Summary of agenda**

The meeting hosts opened the workshop followed by a review of workshop objectives. The work of the WG was reviewed and the participants were introduced to the core set of questions on disability developed by the WG (general measure) as well as the rationale for the approach. Implementation protocols that were developed to test the core set were presented including: objectives of the test and evaluation plan; question by question specifications; translation protocol; plans for cognitive testing; plans for field testing; enumerator training; and plans for data analysis and report writing. UNSD reviewed their work on a questionnaire designed to collect data on disability from countries for use in the Demographic Yearbook. The World Bank reported on pilot testing for a qualitative survey in Kenya. In the wrap-up session, countries were asked to respond to specific questions about their willingness to and opportunities for pre-testing the WG questions in their countries, and were asked for feedback on the questions, the test protocols, and the WG approach to disability measurement including the selected purpose of measurement.

## Issues

### Introduction, purpose and rationale for the question set, and work of the WG

There was significant discussion about the purpose for disability measurement that was selected by the WG and the implications of this choice. There was concern expressed over portions of the population that may be missed using the proposed questions. In particular, groups with certain specific health conditions would be missed by the proposed questions, yet these groups may also encounter significant barriers to participation. How to deal with the type of disability or the presence of multiple disabilities was raised (how can the interviewer determine this). The issue was raised that respondents may have difficulty answering the questions such that their responses fit into one of the categories. The question of how to capture the country specific context was raised; in other words, how to capture factors outside of disability that would aid in the interpretation of the disability statistics that are generated (such as non-disability related factors that might affect employment rates). Participants expressed concerns about the lack of a time reference (i.e. problem lasting 6 months or more). Finally, there was a recommendation about the need for survey modules on disability in addition to census questions because of regularity of these surveys in comparison to the census (both are needed). The need to link statisticians with representatives attending the UN Statistical Commission meetings was recommended by meeting participants.

### Implementation protocols

In general, it was deemed important to involve persons with disabilities and stakeholders in the testing process. Many practical issues were raised; in particular, the need for technical assistance was mentioned repeatedly. There was interest in having more technical assistance than the WG is currently capable of providing. Requests for technical assistance encompassed the need for assistance to conduct the test, conduct a full survey, and use of the data once the census and/or survey is completed. There was concern about raising money to conduct the tests. The question of how to handle non-response and refusals was also raised.

#### 1) Objectives of test and evaluation plan

There was general agreement on the objectives of testing and the plan for evaluation. No specific questions were raised.

#### 2) Question by question specifications and translation

There were many practical issues raised around the issue of translation. Since many African countries use languages that are not written, the question of how to address translation in these situations presents a dilemma. Questions were raised about identifying the best person to perform the translation (i.e. professionals, stakeholders, or staff of national statistical offices). Since some countries have many native languages, the participants asked about the number of languages that should be used for translation. Participants expressed support for the use of conceptual translation. The importance of

adequate training for enumerators, process for verifying the translation, and the importance of the pre-test for translation issues were noted.

### 3) Cognitive test

It was emphasized that cognitive testing was typically conducted in a small sample of 10-30 participants. During cognitive testing the respondents should be probed for an explanation about why they responded as they did, and then see if the explanation matches the respondent's answer to the question. Among the participants there was a perception that the probes might be leading such that they might introduce bias. There was concern that persons with disabilities might not wish to reveal the difficulties they have due to stigma. Questions were raised about how to manage data entry for the cognitive test, perform the analysis, and what to do with the data after the analysis. The need for both country specific analysis as well as comparative analyses across countries from the cognitive test was noted.

### 4) Plans for field test and sample design issues

There were many questions about the nature of the sample (purposeful versus random) as well as the size of the sample needed for the tests. There was concern about how to deal with (identify) different types of disability, multiple disabilities, and levels of severity of disability. These were raised as important issues to address. There was concern raised about proxy versus self-response and whether this should be considered during analysis. It was noted that aspects such as the format of the testing (Census or Survey; Special Study or Small Sample) and methods of dealing with non-responses and refusals needs to be taken into account for the field test. In particular, in some cultures, it may not be viewed as appropriate for women to answer for the household and therefore they might refuse. Cultural issues like this need to be considered. There was concern raised about the order of questions in regards to repetitiveness and in regards to whether on set of questions may condition responses to the next set.

### 5) Enumerator Training

It was suggested that disabled persons should be used as enumerators, and that the word 'disabled' should be avoided during the interview as much as possible because of the negative connotation. The confidentiality clause should be quoted to the respondent. The enumerators should be trained to make disabled respondents feel comfortable and willing to respond to the interview.

### 6) Plans for tabulation, analysis and report writing

It was suggested that prevalence rates should be computed from most inclusive to least inclusive including multiple disabilities. The data should be compared to previous data and prevalence rates. It was suggested that the main aspect of analysis include: 1) correlation analyses between extended and core sets, 2) comparisons of differences in

different populations i.e., by age, sex, rural vs. urban residence; and 3) compare results across countries.

#### 7) UNSD questionnaire

The presentation on Statistics on Human Functioning and Disability stressed the need to measure human functioning and disability and summarized the recommendations provided by the United Nations Guidelines and Principles for the Development of Disability Statistics. It also provided an overview of the collection of data on disability in the participating countries on the basis of the information collected prior to the Workshop through the UNSD Pilot Questionnaire on Human Functioning and Disability Statistics. The presentation served as a basis for the discussion of the UNSD Pilot Questionnaire on Human Functioning and Disability Statistics. For this purpose, three working groups were formed for discussion of a set of exercises and questions previously prepared by the United Nations Statistics Division (UNSD). The replies to these questions and the overall comments of the participants were then discussed by the whole group. During the discussion, a number of proposals were made for a more appealing format of the UNSD Pilot Questionnaire on Human Functioning and Disability Statistics, for an improved wording of the questions and for additional data tables. In particular, the participating countries provided the following suggestions:

1. To include other relevant variables in the collection of data, such as cause of disability and type of disability, as well as educational attainment and occupational status of persons with and without disabilities;
2. To review and reword the questions asking for information on the questions used for determination of the prevalence rates in order to better capture the manner in which the rates were calculated;
3. To review the question on type of data source to encompass the use of screening questions and follow up surveys;
4. To improve the format of the UNSD Pilot Questionnaire on Human Functioning and Disability Statistics to make it less crowded;
5. To send the UNSD Pilot Questionnaire on Human Functioning and Disability Statistics to NSOs every five to ten years, electronically and in hard copy;
6. To disseminate the data and metadata collected through the UNSD Pilot Questionnaire on Human Functioning and Disability Statistics by internet, electronically, and in hard copy.

#### Wrap-up discussion and conclusion

There was general agreement with the proposed questions and purpose of the measure from participating countries and the testing protocols made sense to them. In order to facilitate implementation of the tests, countries were asked to respond via email to the following questions:

- 1) Are you interested in conducting a pre-test of the Washington Group proposed Census questions?

- 2) If so, what opportunities are there for conducting this pretest? For example, are there possibilities for attaching this test to an already planned test or could a separate test be done?
- 3) What parts of the pretest could you conduct (cognitive, field, both)?
- 4) When could such a test be done? We are most interested in finding out about tests that could be conducted by October of 2005 and between October and Jan 2006.
- 5) What kind of financial support would be needed? (I realize you will have to estimate this)
- 6) What kind of technical assistance would be requested?
- 7) What surveys or census activities are upcoming? What are their timelines?
- 8) What surveys are being considered? What do they need to move forward (e.g., approval, funds, TA)?
- 9) Which of these could disability question testing POSSIBLY be associated with?
- 10) Are you interested in implementing a separate disability survey? What do you need to move forward?

All 13 countries attending the workshop responded to these questions and agreed to pre-test. Fifteen countries were offered funding to conduct pre-tests including the 13 countries that participated in the workshop and 2 countries from the African/Middle East region that could not attend the 1st workshop but attended the 2nd workshop. Specifically, \$5000.00 was offered to Kenya, Gambia, and Vietnam to conduct cognitive and field tests; \$1000.00 was offered to India, Philippines, Seychelles, Lesotho, Malawi, Congo, Mauritius, Uganda, Egypt, South Africa, Palestine, and Tanzania to conduct cognitive portion of the pre-test. South Africa can conduct the full pre-test without WG funding. Countries were asked to submit test plans to the implementation workgroup for review prior to receipt of funding. To date, eight countries have submitted test plans.

To the extent possible, the WG will provide technical assistance for pre-tests to countries that request it via email and/or phone contact. The possibility of hiring a consultant for this purpose with funds from the World Bank DGF will be explored.

Next Steps for the Implementation workgroup and participating countries:

1. Cognitive and field test protocols: the analytical plan and the minimum target sample size need to be developed in more detail.
2. A translation protocol will be developed for cognitive test; Income categories at end of cognitive test to be country specific and developed by each country.

3. The workgroup will consider issues about provision of technical assistance and how these issues will be included in questions to countries about conducting the pre-tests
4. Funding: Countries were advised to look for funding in existing programs to build statistical capacity. They were also encouraged to contact the regional World Bank team in Africa since they may be able to provide additional support.
5. An introduction for the cognitive test is to be drafted to assist users with understanding the purpose of the test and to distinguish the cognitive test from the field test.
6. Field test issues such as timing, funding, technical assistance need to be thought through by each country.

The next regional meeting will be held in Rio for two days followed by three days for the 5<sup>th</sup> Annual Meeting of the Washington Group.