Second regional workshop Washington Group on Disability Statistics September 19-20, 2005: Rio de Janeiro, Brazil

Purpose

The Rio regional workshop was primarily directed toward countries in Latin America and the Caribbean who are interested in including disability questions on their national censuses. In addition, there was interest in determining what countries are prepared to do in terms of testing and implementation of the Washington Group questions and to get feedback relative to testing plans.

Participants

Representatives from the National Statistics Offices of the following countries took part in the second regional meeting: Antigua and Barbuda, Argentina, Bahamas, Barbados, Belize, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, Egypt, Guatemala, Haiti, India, Mexico, Occupied Palestinian Territory, Panama, Paraguay, Peru, Philippines, Saint Vincent and the Grenadines, South Africa, Saint Lucia, Trinidad and Tobago, Turks and Caicos Islands, Uruguay and Viet Nam. Inter-American Development Bank and United Nations Statistics Division were the two international organizations that participated in the meeting. Brazil, Ecuador, and Panama had representatives of people with disabilities in the meeting.

Summary of Agenda

The program included an introduction to the short set of Washington Group questions on disability and an explanation of the rationale for the question set. In addition, testing protocols were presented which outlined: the objectives of the test and evaluation plan; the plans for cognitive and field testing; translation protocols; enumerator training; sample design; and specifications for tabulation, analysis and report writing. Also, there was a discussion about the approach of the Washington Group on measuring disability worldwide and the applicability of the test protocols in their country.

Opening

Eduardo Pereira Nunes, President, Instituto Brazileiro de Geografia e Estatistica (IBGE) welcomed the participants and stated that the WG work is important for social inclusion and policy development. Izabel de Loureiro Maior, Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência (CORDE) mentioned the change in approach to the way persons with disabilities were included in the census. She discussed that previously people with severe disabilities were targeted but now people with limitation in activities were being included in order to help them overcome environmental barriers. She urged participants to go beyond statistics and explain them well in order to use them to support positive policies.

Summary of Issues Identified

Review work of the WG and UNSD

During the review of the work the key area of discussion focused on the use of proxy respondents. The participants indicated that the number of persons with disability will increase with the use of activity limitation questions. Use of questions such as these will affect policy implementation for example employment quota for persons with disabilities. Another important question that was raised was on the issue of level of severity. The discussion focused on whether to allow a person to assess their own level of disability and what impact would this have to the validity of the statistics thus compiled.

WG short set of questions on disability

One of the key questions raised during the introduction of the short set of questions was how can countries approach a complex topic such as disability with 3 to 5 questions in their national censuses. Also, the issue of permanence of disability and the usefulness of an introduction were raised as was the issue of excluding certain disabilities due to the addressing specific domains and not others. The restricted space on national censuses and surveys and difficulty with cultural comparability on learning disabilities determined the selection of a limited set of core questions.

Objectives of the test and evaluation plan

The importance of international comparability was emphasized and so was the need for an international core set of questions that captures most people with disabilities. At the same time there is no such thing as a single measure of disability, it depends on the purpose of measurement. The WG will do two types of testing, cognitive to identify respondents' understanding of questions followed by field tests to see how questions work operationally in the field. Different countries will do some things differently because of the logistics, resources and state of the art of collection of disability statistics in the respective countries.

Question by question specifications

The issue of enumerators skipping over information provided in brackets was raised as this creates ambiguity for respondents wondering if they have to respond with or without use of glasses or hearing aid. Also, it was bought to the attention that explaining the concept of climbing stairs to respondents in various parts of the world would be a challenge. Taking note of these issues the WG emphasized that it was exactly for this reason that the cognitive and field testing were being planned.

Translation issues

One of the reasons for doing question by question specifications is for translation. These specifications ensure a common understanding of what is being asked in each question by the researchers, translators, enumerators and respondents. The enumerators will be provided with as much information as possible. The original document will be in English and a conceptual translation will take place rather than a technical (literal) translation. The semi-final questionnaire will be translated (for the test) and again when there is a final questionnaire. Enumerators would be given hand cards containing definitions and specific instructions so they understand the objective and how to ask each question.

Plans for cognitive test

Clarification on cognitive interviewing was provided in particular that it was not a survey but an in depth interview of 20-100 people.

Plans for field test

Issues regarding plans for field test included training the enumerator on understanding persons with disabilities. Country experiences (Ecuador) of using persons with disabilities in the training of the enumerators was shared. The issue of lighting and background noise needs to better for everyone, not just people with disabilities. The need to be opportunistic was also discussed in the context of field testing, for example, adding it onto another survey. Since different countries will have different opportunities in how they will carry out their field test it is important to document what each country does.

Plan for tabulation, analysis and report writing

Some guidelines on sample size for prevalence rates were provided. It was suggested that it was best to use all severity levels and then investigate different cut points. A sample size of at least 5000-10000 households is usually needed to obtain a decent sense of prevalence. If countries do not have an idea of prevalence estimates then they should do small test on 400-500 households to get some sense of prevalence. It was highlighted that when using proxy responses, there is a risk of under reporting. Hence it is always preferable to use self-reporting. However, it is sometimes necessary to use proxies.

UNSD Questionnaire on Human Functioning and Disability Statistics

Participants felt that it is very important that disability is considered as one of the major topics for inclusion in the UN Demographic Yearbook. Some participants mentioned that their countries do not compile date with the full disaggregation requested in the UNSD Questionnaire. It was suggested that the questions on non-response and refusal should state clearly whether they relate only to the disability module or to the overall data collection exercise.

Break-out groups

Explanation on the differences between the cognitive test and field test was provided along with sampling and sample size. The WG is setting out to test 6 questions. The field test includes these 6 questions plus an extended set of questions. A purposeful sample (at least 200 persons with disabilities and 200 persons without disabilities) is needed so there are enough cases for quantitative analysis. For the cognitive test the WG recommends 20-100 interviews using the questions provided. Participants were asked to think about a way to alter question 6 on communication which is deemed to be too long. The participants expressed concern that in many countries the institutionalized population are not included and hence the prevalence rates are not accurate. Also, participants expressed concern over the exclusion of persons in refugee camps.

Wrap-up

- A country's national statistics organization can become a member of the WG.
- The WG meetings are held in English with no translation. Translation costs were not envisaged under the project "Support to the Washington Group Disability Statistics" funded by a World Bank Development Grant Facility.
- If countries are interested in doing the testing some limited funding is available.
- Countries were asked to answer the questions on whether they were able to undertake the cognitive and/or field testing of the WG questions.