

Appendix to the Report of the Washington Group on Disability Statistics: Summaries of meeting sessions

Session 1: Opening session

Objectives: To welcome meeting participants and to provide practical information; provide an update on the work of the WG and developments since the last meeting in Brussels, Belgium; and to review the objectives and agenda for this meeting.

Chair: Lene Mikkelsen (UNESCAP)

Rapporteur: Beth Rasch (USA)

Presenters: Keiko Okaido, Lene Mikkelsen (UNESCAP); Jennifer Madans (USA)

Andrew Flatt, Chief of the Statistics Division at UNESCAP welcomed the group and introduced Keido Okaido, Deputy Executive Secretary at UNESCAP, who gave the opening address. Ms. Okaido indicated that the WG meeting was hosted jointly by UNESCAP and the Thai National Statistical Office. She hoped that the regional contribution would assist in the work of the WG. Ms. Okaido emphasized the importance of the WG work. In May 2002, the Biwako Millennium Framework for Action was adopted in Otsu, Japan. This framework recognized that the lack of adequate data impedes development of disability policies and recommended that governments establish national integrated information systems on disability by 2005. In addition, it urged countries to use common definitions and methodologies in developing their disability statistics. UNESCAP, in support of the Biwako Millennium Framework, held two workshops for improving disability statistics and measurement. NSO representatives attending the second workshop (September 27-29, 2004) joined the WG for the first day of the WG meeting. Ms. Okaido welcomed all of the participants, indicating that the current meeting is timely in light of the ongoing UNESCAP activities in the area of disability policy and statistics.

Lene Mikkelsen, Chief of the Statistics Development Section at UNESCAP spoke in more detail about the Biwako Millennium Framework and the related UNESCAP initiatives. At the second workshop for improving disability statistics and measurement that was just held, it was agreed to test a draft set of disability questions and 12 countries volunteered to use identical testing procedures, schedules and protocols. The tests will be carried out over the next 6 months and cover both census and disability module questions. Ms. Mikkelsen provided a brief synopsis of disability data and collections in the ESCAP region. The summary indicated that censuses are a key source of data on disability in the region and highlighted the need for a common conceptual framework and more comprehensive and comparable data on disability.

Jennifer Madans (USA) reviewed activities of the WG and developments since the 3rd meeting in Brussels. She emphasized that the group is focused on international comparability of disability measures, particularly for use in censuses. She delineated the objectives for the 4th meeting:

- 1) Present work on development of the general disability measure (workgroup 1).
- 2) Discuss the proposed plan for implementing the general disability measure (workgroup 2).

- 3) Discuss the proposed approach for development of extended measurement sets (workgroup 3).
- 4) Discuss methodological issues related to full population coverage.
- 5) Discuss strategic issues.

Dr. Madans indicated that the agenda is comprised of presentations of draft position papers followed by focused discussion addressing specific session objectives. Products and a work plan follow each session.

In this document, the proceedings of each session are summarized in terms of agreements, next steps, and unresolved issues.

Session 2: Proposal of draft set of general questions on disability (short form)

Objectives: To discuss the proposed approach in the context of the agreed purpose, criteria, and the relationship to the ICF; and to reach agreement on a set or sets of questions for pilot tests.

Chair: Marijke de Kleijn (The Netherlands)

Rapporteur: Beth Rasch (USA)

Presenter: Jennifer Madans (USA)

Discussants: Gunilla Davidsson (Sweden) and Xingyan Wen (Australia)

Agreements:

- 1) Six domains will be tested; four core domains (walking, seeing, hearing, and cognition) and two additional domains (self-care and communication).
- 2) A severity scale will be used in the response categories (for example, none/ some/ a lot/ unable). The pilot testing will also include a dichotomous scale to allow comparison between the two options.
- 3) Use of assistive technology will be included in the questions on seeing and hearing (for example, do you have difficulty seeing even when wearing glasses or contact lenses).
- 4) We will determine how to deal with assistive technology for the question on walking through cognitive and pilot testing.
- 5) The question on communication needs the introductory phrase “Because of a health condition” so that respondents don’t misinterpret the question as referring to language problems. The other questions in the set do not require this introduction since it is implied. Clarification is needed regarding the types of communication difficulties the question is meant to capture.
- 6) We will test (cognitive and/or pilot test) whether or not to use a reference to duration of difficulty (length of time the problem has existed) in the introduction to the question.

Next steps for workgroup on developing the general disability measure:

- 1) Write a 1-page document explaining the rationale behind the general disability measure, justifying the choice of domains, and summarizing the decisions that were made when formulating the question set. This document will accompany the general question set (short set).
- 2) Since the question set that is being developed is designed to obtain estimates of disability, the workgroup has been asked to address the issue of whether the short set of questions can be modified to be used as a screener.

- 3) Revise the position paper or write a new paper to clarify definitional issues (explain in more detail how the proposed questions capture basic activity), clarify the explanation of the population that will be captured (i.e. the population at risk of participation limitations because of difficulty walking, seeing, etc.), and to discuss how gender issues will be considered and addressed in order to minimize bias.
- 4) Test the 6-question set. Conduct cognitive testing of the question set. Use the results of cognitive tests to develop field test. Issues to be tested include: use of scaled response category versus dichotomous; whether or not to include use of assistive technology in the question on walking; whether the reference on duration of difficulty is needed in the introduction to the question; and identify age cut-points at which meaningful information can be obtained from each question.
- 5) Changes to workgroup membership (list of current members): Barbara Altman (USA), Jeremiah Banda (UNSD), Alicia Bercovich (Brazil), Carlotta Besozzi (EDF), Ken Black (Australia), Emmanuelle Cambois (France), Roberta Cialesi (Italy), Bothaina El Deeb (Egypt), Ahmed Hussein (ESCWA), Nenad Kostanjsek (WHO), Jennifer Madans (USA), Ros Madden (Australia), Maria Martinho (UNSD), Angela Me (UNECE), Horst Posselt (Australia), Elizabeth Rasch (USA), V.M. Tamhane (India), Herman Van Oyen (Belgium), Romulo Virola (Philippines), Xingyan Wen (Australia).

Unresolved issues:

- 1) What issues can be addressed using existing data, cognitive testing, or field testing?
- 2) Will we use the 6-question test to select the smaller core set of questions?

Session 3: Proposed method/s for implementing the general disability measure

Objectives: To develop key components of the plan for implementing the general disability measure including the development of procedures for pilot testing (delineate steps for pilot testing that can be used across countries).

Chair: Jennifer Madans (USA)

Rapporteur: Romulo Virola (Philippines)

Presenters: Bothaina El-Deeb (Egypt) and Alicia Bercovich (Brazil)

Agreements:

- 1) Due to the heterogeneity of countries, the 6-question set should be piloted in as many countries as possible representing all major geographic regions of the world. The following countries have agreed to participate: Argentina, Brazil, Paraguay, Chile, Philippines, South Africa, Egypt, Kenya, and Uganda. Israel and Spain have expressed willingness to participate if needed and if feasible. Daniel Mont (World Bank) offered suggestions for additional countries in which to do pilot testing based on preparations in these countries to include questions on disability on upcoming censuses: Honduras, Guatemala, Panama, and Yemen. He indicated that Laos and Jordan may also be willing to participate if needed and feasible.
- 2) Implementation protocols will be developed in a 4-month timeframe in the following areas: 1) establishing objectives and an evaluation plan for cognitive and pilot testing; 2) establishing plans for report writing including tabulation and analysis; 3) establishing plans for cognitive testing; 4) translation; 5) enumerator training; and 6) sample design issues (such as the number of households to be covered and

identification of other census questions to be included with the disability questions on the pilot test).

- 3) Existing protocols will be used for reference, such as the EU protocol on translation, the UN guidelines, the WHO translation protocol, the interviewer training manuals from Ireland and Vietnam, and documentation on the joint population census for Mercosur countries, Bolivia, and Chile.
- 4) A new workgroup was formed to develop the named implementation protocols. Given the amount of work to be done, it was proposed that a consultant be hired with WB-DGF funds. The consultant would develop the protocols with input from the protocol teams. A team will coordinate the work of small subgroups working on the implementation protocols (protocol teams) and the work of the consultant. WG participants volunteered for workgroup assignments as follows: Coordination team: Joseph Muli-Kalavi (Kenya, IDP), Jerry Banda (UNSD), Pamela Nabukhonzo (Uganda); Objectives / evaluation plan: Joanne Hillermann (Australia), Alicia Bercovich (Brazil), Margie Schneider (South Africa), Howard Meltzer (UK); Cognitive testing plan: no volunteers; Translation: Jean-Marie Robine (France), Ethel Baptiste (St. Lucia); Enumerator training: Anne Good (Ireland), Bothaina El-Deeb (Egypt); Sample design issues: no volunteers; Report writing/ analysis plan: Dan Mont (World Bank).

Next steps for new workgroup on implementation:

- 1) Dan Mont (World Bank) will suggest additional countries that are willing and in a position to participate in pilot testing (at the time of this report, this has already been accomplished).
- 2) Confer with UNSD on whether WB-DGF funds may be used to hire a consultant for this activity.
- 3) Identify the necessary skills and abilities of the consultant to successfully perform this work. Identify and hire the consultant.
- 4) Complete the indicated protocols in a 4 month timeframe.

Unresolved Issues:

- 1) There were no volunteers to work on the cognitive testing plan protocol or the sample design protocol. Volunteers need to be solicited to assist in this work.
- 2) We do not currently have geographic representation of major regions for pilot testing. Do we need it?
- 3) The number of countries needed for pilot testing must be determined.
- 4) The role, if any, of WG members in overseeing the implementation of pilot testing needs to be identified.
- 5) This workgroup needs to identify a workgroup chair.
- 6) Methods for enhancing representation of persons with disability in the formulation of the implementation plans need to be identified.

Session 4: Proposed approach for development of extended measurement set/s

Objectives: To decide on the purpose/s of extended measurement set/s; identify other pertinent issues associated with fielding such questions (such as venue, individual country needs [i.e. war affected areas], complexity, characteristics of the set/s, whether to develop one or many set/s, international comparability, etc.); and to develop priorities for additional work to be accomplished.

Chair: Pamela Nabukhonzo (Uganda)

Rapporteur: Gary Catlin (Canada)

Presenter: Marijke de Kleijn (The Netherlands)

Discussants: Marguerite Schneider (South Africa), Jennifer Madans for Barbara Altman (USA)

Agreements:

- 1) The purpose of the first extended set to be developed is assessment of equalization of opportunities.
- 2) Additional questions are to be developed that are related to the current six domains covered in the short question set and, in addition, questions are to be developed on new domains.
- 3) The extended set of questions is to be a module that will go into other existing national surveys.
- 4) Better representation of developing countries is needed for this workgroup.
- 5) A paper is needed explaining what is meant by participation and examining aspects of participation (P) that are and are not covered in current surveys. In addition, the paper will discuss how environmental factors (E) are to be included and how the “at risk” population identified via the extended set links to P & E.
- 6) Additional volunteers for this workgroup are needed and were solicited as follows: Daniel Mont (World Bank), Romulo Virola (Philippines), Joseph Muli-Kalavi (Kenya, IDP), Margie Schneider (South Africa), Anne Good (Ireland), Barbara Altman (USA), and Nevin Uysal (Turkey).

Next steps for workgroup on extended measurement set/s:

- 1) Workgroup 3 will develop a paper identifying what indicators will be used to demonstrate equalization of opportunities, specifying the justification for the extended set, and discussing how gender issues will be considered and addressed to minimize bias.
- 2) In the same paper (as above) or in a separate paper, Marijke de Kleijn (The Netherlands) and Margie Schneider (South Africa) agree to examine the domains of participation and environment and how they relate to the proposed extended set. Questions on the environment that already exist in national surveys will be identified and gaps highlighted.
- 3) This workgroup will develop one extended set of questions to address the purpose of assessing equalization of opportunities, expanding on the six domains identified for the short general measure (more detail) and adding questions on additional domains that reflect basic activities (i.e. willful action). A second extended set will be developed encompassing more complex activities/limitations, participation/restrictions and environmental factors.
- 4) Joseph Muli-Kalavi (Kenya, IDP) will provide names of representatives from disability organizations who might wish to participate in the workgroup to the leader (Marijke de Kleijn, The Netherlands).

Session 5: Discussion of methodological issues related to full population coverage

Objectives: To identify the impact of excluding the institutionalized population and children from disability surveys and discuss problems and approaches for covering the full population.

Chair: Gary Catlin (Canada)

Rapporteurs: Ethel Jn. Baptiste (St. Lucia) and Mathilde Sector (Austria)

Presenter: Howard Meltzer (United Kingdom)

Discussants: Pamela Nabukhonzo (Uganda), Joseph Muli-Kalavi (Kenya, IDP)

Agreements:

- 1) The issue of persons excluded from national surveys is important. Differences in who is excluded from national surveys across countries may affect the comparability of our disability measures. The impact of excluding “floating populations” is important especially in developing countries.
- 2) We need to look within each country to see who is excluded from national surveys; whether it is feasible to include them; and whether our questions are relevant for these populations.
- 3) The issue of effects of proxy response and non-response also need to be considered by the WG.
- 4) The issue of inclusion of children is important because in some developing countries, children work, are heads of households, and are soldiers; they may not attend school.
- 5) We will pilot the general questions (short set) on persons aged 5-17 years of age to determine whether we are obtaining useable (valid) data.

Next steps:

- 1) Include discussion of excluded populations in the protocol on implementation (possibly in the survey sampling section).
- 2) Pilot the six recommended questions on children aged 5-17 years in order to make an informed decision on the appropriate ages to include in surveys using our general measure (short set).
- 3) Address the issue of proxy and non-response via a paper by Howard Meltzer (UK) which will be presented and discussed at the next (5th) meeting.
- 4) Questions will be included on the next country report to 1) identify groups excluded from national surveys; 2) identify the magnitude of this exclusion (estimate the size of the groups); and 3) to identify what data collection efforts exist for these groups.
- 5) Mathilde Sector indicated she would establish an inventory of instruments used in defining children with disabilities internationally and examine how each instrument covers ICF domains.

Unresolved issues:

- 1) Existing experiences and papers on excluded populations need to be included in question documentation. How will this be done? Will a reference list be developed? Who will do this work?
- 2) The need for additional question versions on children should be evaluated when developing the extended sets.
- 3) Ways to determine if it’s feasible to include excluded populations need to be developed. A session on this topic should be included at the next meeting.

Session 6: Strategic issues

Objectives: To review country reports in order to identify potential venues and timing for pre-testing; plan for use of World Bank Development Grant Facility funds for pre-testing and provision of technical assistance; and discuss governance issues.

Chair: Alicia Bercovich, Brazil

Rapporteur: Beth Rasch, USA

Speakers: Marijke de Kleijn (The Netherlands), Daniel Mont (World Bank), Romulo Virola (Philippines), Nevin Uysal (Turkey), Jeremiah Banda (UNSD), Beth Rasch (USA)

Agreements:

- 1) Several countries in Central America will move forward in the near future with disability surveys and at least 2-3 are willing to be involved in pre-testing using the question set/s developed by the WG. We should align ourselves with that momentum and coordinate our timeline for pilot testing so that these countries can be included in our pilot work.
- 2) The following countries are preparing for data collection efforts on disability (censuses and surveys) within the next 3 years and may be potential venues for pilot testing questions developed by the WG: Egypt, Palestine, Peru, and the Philippines will be conducting censuses and Estonia, Hong Kong (China), Ireland, Kenya, New Zealand, St. Lucia, and Spain will be conducting surveys.
- 3) Information provided in the country reports on the prevalence of disability and data collection methods is valuable. The results should be collated and analyzed to try to understand the reasons for disparate results.
- 4) It would be useful to know about types of pre-testing that WG countries are doing and to know what countries have ICF translations.
- 5) Data collection activities, including protocol development, are a priority for use of the WB DGF funds (hiring consultant to develop implementation protocols and conducting pre-testing).
- 6) It was agreed that WG members would provide technical assistance to countries piloting our questions if the need arises (formal request made from the country) and if WG members are prepared to provide such assistance.
- 7) Jennifer Madans (USA) was selected to serve a 3-year term on the Steering Committee.
- 8) UNSD will hopefully piggy-back regional statistical meetings on disability with WG annual meetings. Therefore, regional meetings do not need to be in the WG long-range plan as a distinct WG activity.
- 9) It was agreed that development of an international compendium of disability statistics would be considered as a long-range goal of the WG once more internationally comparable data are available for comparison.

Next Steps:

- 1) There is overlap between the work from the Joint UNECE/WHO/Eurostat Meeting on the Measurement of Health Status and the work of the WG. Therefore, we will report WG results to this group to try to minimize duplication of work. Their next meeting will be held in November 2005.
- 2) UNSD offered to work on analyzing the country reports to better understand disparate prevalence estimates on disability. The WG secretariat will provide UNSD with country reports from the 1st and 3rd meetings in order to complete this work. UNSD will gather additional information from countries that submitted reports to the WG and will combine this information with data they have collected from countries that have not been involved in the WG. They will report on this work at the next (5th) WG meeting.

- 3) Two questions will be added to the country questionnaires for next year: 1) Have pre-testing activities taken place in the last year and if so, please describe these activities; 2) Is the ICF translated into language/s appropriate for your country?
- 4) The WG secretariat will formally invite Turkey (via the President of the State Institute of Statistics) to participate in the workgroup on extended measurement sets because of their experience using general and extended measurement sets.
- 5) The workgroup on implementation needs to determine the funding needs of countries who have expressed willingness to be involved in pre-testing the general measure so that we can better plan use of the WG-DGF funds.
- 6) The topic of harmonization of health and disability data using modern calibration techniques will be introduced at the 5th WG meeting in Brazil. Bedirhan Ustun (WHO) agreed to present on this topic and possibly chair this session. The session would aim to examine multi-method approaches to comparative assessments of self-report and measured data to reduce artifacts due to self-report and suggest ways to improve survey implementation.

Session 7: Next steps and objectives for the 5th meeting in Brazil

Objectives: To summarize the accomplishments of the 4th meeting and outline next steps; announce the date and location of the 5th meeting and determine objectives; solicit volunteers to host the 7th WG meeting; and to close the 4th meeting.

Chair: Jennifer Madans, USA

Rapporteur: Marijke de Kleijn

Speaker: Jennifer Madans, USA

Agreements:

- 1) The Executive Summary for the 4th WG meeting will be sent to the full membership for comment.
- 2) It was agreed that a new workgroup was needed to address methodological issues in addition to full population coverage such as the issues of proxy and missing responses, and the effects of mode of administration. The following WG participants volunteered for this workgroup: Howard Meltzer (UK), Montserrat Lopez-Cobo (Spain), Mathilde Sector (Austria), Gary Catlin (Canada), Jorun Ramm (Norway), and Pamela Nabukhonzo (Uganda).

Next steps:

- 1) The workgroup on implementation will deal with the question of which issues will be addressed using existing data, cognitive testing, or field testing. This workgroup will also plan for how to choose 4 final questions from the 6 questions that will be tested as part of the protocol for establishing objectives and an evaluation plan for the cognitive and pilot testing.
- 2) The workgroup on development of the general measure (workgroup 1) will revise the 6 questions (short set) proposed at the meeting, send them out to the WG for comments, and decide on the final questions to be tested by December 2004.
- 3) The workgroup on extended measurement sets (workgroup 3) will suggest a small extended question set (using existing questions) that can be tested simultaneously with the short general measure. This will provide additional information about the core domains being tested with the short general question set.

- 4) The 5th WG meeting will be held September 21-23, 2005 in Rio de Janeiro, Brazil. Objectives for the 5th WG meeting are to:
- a. Present work on continued development of the general disability measure including revisions based on the results of cognitive and pre-testing (workgroup on general measure);
 - b. Present work on the written protocols and plan for implementing the general disability measure including lessons learned from pre-testing (workgroup on implementation);
 - c. Present work on the development of the extended measurement set and the associated paper on its' relationship to participation and the environment (workgroup on extended measures);
 - d. Discuss methodological issues related to proxy and non-response; continue discussion of full population coverage including a report on data collected from WG country representatives on groups excluded from national surveys and a report on the results of pre-testing the general disability measure with children 5-17 years of age (workgroup on methodological issues);
 - e. The Steering Committee chair will lead a discussion on strategic issues.

Jennifer Madans ended the 4th meeting by thanking our hosts, UNESCAP and the Thai NSO, the WG Steering Committee, and the WG participants for their valuable contributions to the work of the WG.