

1290 respondents. Inconsistencies were found between the WG questions and the follow-up questions. Reasons for inconsistencies included:

- True response error (in WG question or follow-up questions)
- Characteristics of respondents disability that were not captured in follow up questions
- Data entry/Interviewer error

The question remained: How do inconsistencies affect prevalence and identification of type of difficulty? Analyses revealed that using the threshold of 'Some difficulty' to define disability yielded more inconsistent responses than 'a lot of difficulty'.

Higher rate of inconsistencies were found in the in cognition and self care domains.

Conclusion: WG short set is useful in identifying people for prevalence of disability – very few false positives.

- 2) Assessment of how each question captures functional limitations within its specific domain; i.e. to what extent does each question falsely identifies people as having a disability and what are the reasons for misidentifications and which population(s) are most likely to be misidentified.

Misidentification can occur for a number of reasons. It is important to determine whether false positives or negatives are occurring systematically or randomly. For cases identified as 'true errors', determine if there is any association with gender, country, age, disability or health status. The true errors identified for the vision question were more than likely related to the glasses clause and misunderstanding of the question. There is a potential for false positives in the extended questions on cognition as a high rate of inconsistencies was found; however, unlike the vision question, the inconsistencies are more likely to be a result of interpretation issues and not obvious misunderstanding.

Conclusions:

- WG questions taken as a group are good at generating general prevalence estimate
- Confirm that glasses clause is significant issue, but needs to be addressed at country level – language, custom
- Country differences in response error are significant -- suggests need for country specific cognitive testing in question development
- Preliminary results suggest no real sign of demographic bias

- 3) Assessment of the potential of WG Short Set as screener

Data from Canada was used to evaluate how the WG questions compared to more detailed questions. In Canada a census was used to develop a frame for a disability survey. The Participation and Activity Limitation Survey (PALS) was carried out as a post-censal survey with additional follow-up studies. That allowed for the testing of false positives, false negatives and the performance of the WG questions. Face to face interviews were then conducted with 50 false positives, 100 false negatives and 50 "soft" disabilities (e.g. learning, etc. who are normally difficult to identify). The WG questions were included in all interviews.

Findings: The WG questions seem to miss emotional/psychological disabilities, learning disabilities, agility disabilities and mild to moderate pain disabilities.

As a screener the WG questions are easily understood, concise and appropriate to a Census, and appropriate to proxy response. However, they are less adaptable in terms of being inclusive of all types of disabilities and covering all age groups

Workgroup 3 was to draft a position paper specific to developing an extended question set for the purpose of assessing equalization of opportunities. The position paper was to include the plan, purpose, and approach for developing the extended set. It was agreed that the primary issue for this extended set is expansion of the existing domains covered in the short set and adding to the existing domains. The WG will be collaborating with UNESCAP on development of the extended set/s.

In its proposal for Extended Question Sets, the following principles were agreed upon for the development of extended set(s) of questions:

- 1) Feasibility and cross-country comparability
- 2) ICF framework (terminology) as a basis
- 3) Review of existing sets as a basis for further development
- 4) Congruency and coherence between short and extended sets

The purpose of extended sets will be to address issues of equalization of opportunities and the determination of disability prevalence. In addition, data derived from the extended sets will be used for the individual needs of the country collecting the information (policy development, advocacy, monitoring and evaluation of interventions, international reporting, and providing summary measures on disability in general or individual impairments).

The compilation of extended set(s) will require the resolution of several issues:

- 1) a closer look at “cross-country comparability” and what some of the limitations may be in meeting this requirement
- 2) a discussion of how the extended set(s) will serve the stated purpose of “equalization of opportunities”
- 3) the specific wording of questions and response options (4 vs. 5 answer categories)
- 4) how to best measure environmental factors
- 5) Choice and desire – the issue of needing or wanting to do the activity

Future work should focus on:

- Deciding on the structure of the proposed extended set(s) (includes purpose, nature and number)
- Compiling the sets
- Building an evidence base (cognitive testing, statistical analysis of existing data)
- Analysing and reporting (summary measures, individual question responses, prevalence estimate, deciding cut off point)
- Developing guidelines

There was general agreement that there should be (at least) two extended sets.

- The first set would build upon the Short Set, re-visit domains excluded from Short Set and further develop Short Set domains. Additional domains would include: upper body functioning, psychological functioning, expansion of the cognition domain, fatigue*, and pain*. (*The consensus was that pain and fatigue should be included. However, the method of inclusion, as separate domains or as characteristics of other domains, will be addressed by the Extended Sets workgroup.)

- The second set would be used to get more detailed information. There was consensus on a need for questions on cause, age of onset, duration and environmental factors (including assistive technology and assistance and environmental barriers/facilitators).

With respect to basic and complex activities: The objective would be to extend the information collected on the basic activities (Short Set) in order to explain more complex activities (participation). This is complimentary to equalization of opportunity. In order to assess how a person improves their participation in society (e.g. through education, employment etc.) questions on assistive devices/environmental factors need to be included in each domain. These participation questions are important with respect to policy.

In summary, there was agreement to work with UNESCAP in the development of extended set(s). Also, the Extended Sets workgroup will:

- Re-visit the Short Set of basic activity (functioning) domains (adding possibly multiple questions to certain domains)
- Decide on the use of an upper body domain
- Decide on the inclusion of supplementary questions within domains (cause, onset, duration, etc...)
- Decide on how best to capture environmental factors (micro, meso, and macro levels)
- Explore different ways to measure participation

Furthermore, the workgroup will:

- Coordinate work with the work of other groups (BI, Eurostat, UNESCAP)
- Compile list of questions being used in other workgroups
- Determine timeline for extended set
- Determine who wants to be involved in the Extended Sets Workgroup. (Margie Schneider, chair)

Other agenda items

In addition to the sessions reporting on workgroup activities, updates were presented from the United Nations Statistical Division, UN affiliates, and the World Bank about their activities related to disability statistics, as well as country specific presentations. Finally, the Steering Committee chair led a discussion on strategic issues including planning the next steps.

Harmonizing work on Extended Sets with the Budapest Initiative, health-related Eurostat projects and UNESCAP - UN Development Account Project on Improvement of Disability Statistics: The importance of coordinating and linking with the activities of other groups in the field was stressed. WG will prepare a proposed strategy to maximize synergy in the work of the Washington Group, the Budapest Initiative and the UNESCAP Disability Project. This strategy will be distributed to the Steering Committee. In addition a copy of the Eurostat questionnaire will be requested.

Technical Assistance to NSOs: The Washington Group has completed its work on the short set of disability questions to be included on Censuses. A survey by UNSD suggests that some technical assistance is needed in the area of implementation, interpretation and analysis of disability questions on Censuses. To fill this need, the Washington Group proposes to develop two documents that address issues related to the adoption of the new

question set on Censuses. In particular, issues related to how to interpret the data produced by the questions will be addressed. One document will be designed for use by the NSO and one for use by policy and advocacy groups. Other possible activities include:

- development of a presentation and a packet of materials to be used at regional workshops or technical assistance meetings on the 2010 Census Round;
- participation of WG members at regional workshops or technical assistance meetings on the 2010 Census Round;
- provision of technical assistance by WG members as requested by NSO's

If there is agreement on these activities, the WG steering committee chair will contact the Director, UNSD to discuss next steps.

The World Bank Project: United Nations (UN) approached the World Bank (WB) with an idea for developing a set of indicators to monitor the implementation of the UN Convention on the Rights of Persons with Disabilities. It was proposed that the WG develop a tool for monitoring based on the short set of questions and further development through the extended set. Funds for this project would be raised through the World Bank Donor Trust Fund and would be allocated to pay for consultant services to assist the group in developing the tool (extended set), cognitive testing in several countries, and to fund a special meeting of countries for final agreement. If there is agreement, a proposal is required

The meeting agreed to take on the World Bank Project

Country presentations:

1) Report on the Irish Census

In 2004 the Government decided to conduct a post-censal National Disability Survey to establish prevalence, severity and impact of disability in Ireland and to identify improvements needed in policy and service provision. A sample was based on responses to the 2006 Census questions on disability. Questionnaires were developed in consultation with NDA, Government departments, representative groups, and disability research experts.

Conclusions: Matching NDS records to Census at the person level increases the statistical value of NDS output. A high proportion of the Census false positive responses are due to responses in the 'Other' category. Less than 3/4 of the sample reported a disability in both surveys. The Census questions/methodology resulted in a much higher level of single disability reporting than in the NDS. Learning related difficulties were prevalent among children while mobility and pain were most prevalent disabilities for older people, and people of working age had a more mixed range of reported difficulties.

2) Report on Three Country Pilot Study - Brazil (IBGE), Argentina (INDEC) and Paraguay (DGEE)

The pilot study was carried out in November 2006: interviews were conducted in Brazil (4039), Argentina (1903) and Paraguay (2009). Information was collected on disability (core, extended, and IBGE questions), housing and demographic characteristics.

Findings: In all countries WG questions identified more people than the extended sets especially at the D1 (minimum response to WG questions is *some difficulty*) and D2

(minimum response is *a lot of difficulty*) levels, and at D3 (minimum response is *can't do it at all*) the opposite was found, where higher rates were observed in the extended sets. In Brazil a single vision question captured less people than 2 questions.

3) Report on Uganda Pilot Study

A pretest of the 6 WG questions was part of the 2006 Uganda Demographic and Health Survey (UDHS). Data were collected between May and October 2006 and included 8,870 households selected from 368 EAs (clusters) covering the entire country. The disability questions were administered to all household members over 5 years of age.

Findings: Vision, hearing, walking, and cognition difficulties increase with age while self-care difficulties present a U-shaped curve and communication difficulties increase sharply at age 50-59. The prevalence of recorded difficulty in at least one functional area increased drastically at age 30, with overall most people falling into the category "some Difficulty". A clear challenge will be to consider levels of severity in the computation of disability prevalence.

4) Introduction to Surveys and Research on Disability in China

National Sample Surveys on Disability in China are planned every 20 years. To-date surveys have been carried out in 1987 and 2006 with annual monitoring using smaller samples. The Institute of Population Research at Peking University is responsible for these activities. In addition, the China Disability and Development Research Center has recently been established at Peking University as the first national institute on Disability Studies.

An International Forum on Disability and Development was planned for December 10-15, 2007.

5) Functioning and disability in Europe – Measuring Health and Disability in Europe (MHADIE) project results: ICF Functional profiles in 12 selected health conditions in Europe. MHADIE is a three-year Coordination Action financed by the EU Commission, involving 16 European Centres and 10 different countries. It aims to demonstrate the utility and feasibility of ICF model in measuring different types and prevalence of impairments and limitations.

Data were collected on health conditions: Bipolar Disorder, Depression, Ischemic Heart Disease, Migraine, Multiple Sclerosis, Musculoskeletal Conditions, Parkinson Disease, Stroke, Traumatic Brain Injury; Demographic information: nationality, gender, age, marital status, educational level, current job, risk factors (smoke and alcohol consumption); and Functional outcomes and profiles: The ICF Checklist, The WHO Disability Assessment Schedule (WHODAS II), The Health System Responsiveness and Satisfaction with Health Care (HSR&S) scale, Short Form 36 (SF-36), The WHO Quality of Life Questionnaire (WHOQoL).

It was found that ICF-based datasets demonstrate the utility of the ICF and its related tools in describing functioning, health and disability across a variety of settings, clinical conditions and countries. ICF can be graphically represented to compare clinical samples for different variables: health condition, clinical setting, age group or country.

The correlations between ICF data and selected clinical variables demonstrates that ICF provides a common base of data for distinguishing functional patterns among different

conditions, but also gives the possibility of drawing functional profiles besides the health condition.

Governance issues

The 8th WG meeting will be held October 29-31, 2008 in Philippines.

In keeping with UN guidelines, issues of gender bias and other potential sources of bias will be a consideration of all WG work.

Products

Proceedings from the meetings (presentations and papers), reports to the UN Statistical Commission, final meeting reports, and information on upcoming meetings can be accessed through the Washington Group website, currently hosted by the National Center for Health Statistics, U.S.A. (<http://www.cdc.gov/nchs/citygroup.htm>).

WG Points of contact: Washington Group Secretariat (NCHS, U.S.A.)

Cordell Golden
Statistician
National Center for Health Statistics
3311 Toledo Road, Room 6428
Hyattsville, MD 20782 (USA)
(Phone) 301-458-4237
(Fax) 301-458-4038
(Email) CGolden@cdc.gov

Mitch Loeb
Associate Service Fellow
National Center for Health Statistics
3311 Toledo Road, Room 6435
Hyattsville, MD 20782 (USA)
(Phone) 301-458-4248
(Fax) 301-458-4037
(Email) MLoeb@cdc.gov

Jennifer Madans
Associate Director for Science
National Center for Health Statistics
3311 Toledo Road, Room 7202
Hyattsville, MD 20782 (USA)
(Phone) 301-458-4500
(Fax) 301-458-4020
(Email) JMadans@cdc.gov

Eighth Annual Meeting of the WG: Objectives and Agenda

Jennifer H. Madans
U.S.A.

Summary of annual meetings

- 1st meeting - Washington, DC, Feb 2002
 - 2nd meeting - Ottawa, Canada, Jan 2003
 - 3rd meeting - Brussels, Belgium, Feb 2004
 - 4th meeting - Bangkok, Thailand, Sept 2004
 - Regional workshops:
 - Nairobi, Kenya, June, 2005
 - Rio de Janeiro, Brazil, Sept 2005
 - 5th meeting - Rio de Janeiro, Brazil, Sept 2005
 - 6th meeting - Kampala, Uganda- Oct, 2006
 - 7th meeting - Dublin, Ireland - Sept 2007
-

Milestones:

1. Agreed to develop short and long sets of internationally comparable disability measures using the ICF as a framework; census questions a priority
 2. Established link between purpose and aspects of measurement
 3. Equalization of opportunities selected as purpose of short measure
 4. Draft of short measure agreed upon conceptually; revisions to the questions, statement of rationale, and test implementation protocols completed
-

Milestones (continued):

5. Informed countries about the questions, the planned pre-testing, and the pre-test protocols and sought feedback from countries on these activities
6. Revisions suggested for the short set, the accompanying rationale, and the implementation protocols. New workgroup formed to plan and implement analyses of the WG pre-tests
7. Short set adopted. Plans laid for the development of extended question sets.

From Dublin to Manila:

- 7th Annual Meeting (Dublin, Ireland - September, 2007):
 - The meeting was attended by 58 persons:
 - 25 representing national statistical authorities from 22 countries
 - 22 representatives from national institutes of public health or other national research bodies or ministries
 - 7 representatives from international organizations (UNSD, UNESCAP, World Bank, WHO, UNECE, Eurostat, European Disability Forum)
 - 4 representatives from the National Center for Health Statistics
-

Major accomplishments in Dublin

- Agreement on how to approach the development of the extended sets
 - Expand the number of functional areas
 - Expand the kind and amount of information obtained about each functional area
 - Compile list of questions being used in other workgroups
 - Agreement to coordinate work with other groups (BI, Eurostat, UNESCAP) and develop a Matrix to illustrate commonalities and to guide in the development of the extended sets
 - Use a multi-factorial approach to measuring the environment: micro, meso, marco
-

Major accomplishments since Dublin (extended sets)

- Development of the Matrix of WG activities used to guide the extended question sets
- Compiled lists of questions being used in other workgroups: Canada, Australia, Norway (SINTEF), Ireland, Eurostat, UNESCAP, Tanzania
- The Joint WG / BI / UNESCAP Meeting held at National Center for Health Statistics, 8-10 July 2008
 - Discussed the development of the extended question sets
 - Developed the proposal that will be presented and discussed at this meeting

Major accomplishments since Dublin (collaborations)

- UNESCO collaboration:
- WG participation in 2 Bangkok meetings sponsored by the World Bank and UNESCO
- UNESCO agreement to sponsor 6 countries in the cognitive and field testing of the extended question sets

Major accomplishments since Dublin (reports)

- Reports completed:
 - Disability Information from Censuses, prepared for DPOs
 - Development of an Internationally Comparable Disability Measure for Censuses, prepared for NSOs
 - Monitoring the UN Convention on the Rights of Persons with Disability
- Draft report prepared:
 - Understanding and Interpreting Disability as Measured using the WG Short Set of Questions

Plan for 8th meeting

- Focus of the meeting on the development of the extended question sets
 - We want to reach agreement on the proposed extended set of questions
 - We want to discuss the development of other possible sets of questions (e.g. environmental factors)
 - Discuss plans for cognitive and field testing of the extended sets
 - Prepare for the analysis of the test results
 - Discuss further implementation
-

Major objectives WG-8 (Session 2)

- Development of Extended Question Sets
 - Establish the background & guiding principles to the development of extended question sets
 - Present the Matrix & lay the groundwork for the development of the extended question sets
 - Present the proposed extended set of questions
 - Agree upon an extended set of questions for testing
-

Major objectives WG-8 (Session 3)

- Cognitive and field testing of the extended question sets
- Present the UNESCO collaboration
- Present the cognitive test procedure and lay the groundwork for understanding qualitative research methods
- Present the field testing protocols
- Outline the timeline to completion

Other objectives WG-8 (Sessions 4-9)

- Methodological issues concerning surveys
 - Review of outstanding methodological issues (children, proxy respondents)
 - Presentation of WG reports
 - Updates on other WG and collaborative activities
 - Country reports
 - Potential funding opportunities
 - Preparing for the future: next steps
 - 9th meeting of the WG
 - Recruitment & preparations for testing
-

WG 8th meeting Manila, 29 – 31 October 2008

Session 2: Background and guiding principles – extended sets

1. Introduction of background and purpose of the extended sets

Please refer to the documents presented at the 7th Meeting of the WG in Dublin (Sept 2007) for background on the proposals.

This section will reiterate the purpose of the extended sets and present the structure of the proposed sets.

The Purpose of the extended sets is to measure equalisation of opportunities which is the same as that of the Short Set for Censuses. The extended sets are to be used in surveys where there is more space to ask more questions in order to identify the target population as for the Short Set (i.e. people at risk of experiencing discrimination and disadvantage in life opportunities because of limitations in one or more basic activity domains).

When measuring disability it is important to include the following steps:

1. **Identify the population at risk:** This is done by both the Short Set in Censuses and the extended sets proposed below in surveys. The identification becomes a demographic variable just as sex, age and geographic area are currently used. The demographic variable can be used to measure disability with varying degree of detail.¹
2. **Describe the experience of disability** by the population identified as being at risk. This information is obtained by analysing the employment and education status, social inclusion, access to basic and other services, poverty, disadvantage, discrimination, etc., and the effect of different levels of environmental factors (assistive devices and personal assistants, physical and built environment, social support and attitudes, services, systems and policies) by disability status using the demographic variable (+ other variables such as age of onset, etc.). The questions posed to measure these other aspects are either.....
 - those used by the country for employment, education, etc. and not specifically part of the extended sets

OR

 - those developed specifically as part of the extended sets to ensure that aspects relevant to people with disabilities are covered (e.g. use of transport) and that the response options reflect their experiences as well (e.g. 'Why are you not working?' – to include 'Attitudes of employers' together with other response options).

¹ The creation of this variable as a binary or other variable is a separate issue to be discussed in a session on methodology in future WG meetings. Furthermore, the extent to which the identification of the population at risk is comprehensive or complete is also a separate issue to be discussed.