

CONFERENCE OF EUROPEAN STATISTICIANS

Third Meeting of the 2012/2013 Bureau  
Luxembourg, 5-6 February 2013

For discussion and recommendations
---------------------------------------

Item 5 of the Provisional  
Agenda

**COORDINATION OF INTERNATIONAL INITIATIVES  
ON HEALTH AND DISABILITY STATISTICS**

**Prepared by the secretariat**

**I. INTRODUCTION**

1. In December 2012 the WHO and the World Bank organized an expert meeting in Geneva to develop a Model Disability Survey and review a draft disability survey questionnaire. However, the preparation of the questionnaire does not take into account the results of the work of other international initiatives in the same field, such as the Washington Group on Disability Statistics and the Budapest Initiative on the Measurement of Health Status, and there are no plans to systematically involve the national statistical offices in the Survey.

2. This note presents, in section II, information on the three initiatives on the measurement of health status and of disability: the Budapest Initiative, the Washington Group, and the new Model Disability Survey recently promoted by WHO and the World Bank. Section III discusses coordination issues related to the development of the Model Disability Survey.

**II. PROGRESS OF THE VARIOUS INITIATIVES**

**A. Budapest Initiative on the Measurement of Health Status**

3. The Budapest Initiative (BI), established in 2005 under the Work Programme of the Conference of European Statisticians, is a collaboration of, among others, the World Health Organization (WHO), United Nations Economic Commission for Europe (UNECE) and Eurostat. Its main purpose is the development of an internationally accepted standard set of questions for assessing general health state in the context of population interview surveys.

4. The BI Task Force developed a question set based on the results of various rounds of cognitive and field testing, carried out in conjunction with testing exercises promoted by the Washington Group on Disability Statistics. The Bureau endorsed the final report<sup>1</sup> of the BI Task Force, including the question set, in November 2011. It is available on the UNECE website as an electronic publication with the title "Survey Module for Measuring Health State".<sup>2</sup>

---

<sup>1</sup> ECE/CES/BUR/2011/NOV/7/Add.1

<sup>2</sup> [http://www.unece.org/publication/survey\\_module\\_measuring\\_health\\_state.html](http://www.unece.org/publication/survey_module_measuring_health_state.html).

5. The BI Steering Group will continue until October 2013 to provide a focal point to countries for sharing experiences on measuring health status and disseminating the results of the work of the BI, in compliance with its Terms of Reference.

#### **B. Washington Group on Disability Statistics<sup>3</sup>**

6. The Washington Group on Disability Statistics is a City Group established by the United Nations Statistical Commission in 2001. Its main purpose is the promotion and coordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. Its major objective is to provide basic necessary information on disability that is comparable throughout the world.

7. The Washington Group has sought to foster international collaboration and in particular to ensure that the efforts of the Group are broadly based and take into account also the specific needs of developing countries from every region of the world. Thus, representatives of national statistical authorities, disabled people's organizations and international organizations participate in the Washington Group, including UNSD, WHO, UNECE, UN-ESCAP, UN-ESCWA, ILO, OECD, the World Bank, and Eurostat.

8. A major accomplishment of the Washington Group has been the development, testing and endorsement of a short set of questions that can be used on censuses and surveys. These questions are based on the model of disability inherent in International Classification of Functioning, Disability and Health (ICF) developed by WHO, and contain a particular emphasis on international comparability. Testing procedures designed for the evaluation of internationally comparable question sets were developed for the use of the Washington Group.

9. The Washington Group has also developed an extended set of functioning questions to be used as components of population surveys, as supplements to surveys or as the core of a disability survey for use in surveys that expand on the short set.

10. Currently, the Washington Group is conducting additional work in the following areas:

(a) Short set of questions: further analysis of questions used in the 2010 round of censuses and resulting estimates of disability (based on information collected by countries); preliminary results were presented at the 12th meeting of the group (Bangkok, October 2012);

(b) Extended set of questions on functioning: further analysis of data from the United States National Health Interview Survey;

(c) Development of questions on child functioning and disability;

(d) Extended sets of questions on environmental factors and participation: conceptual framework and feasibility of developing a proposed set (or sets) of questions measuring environmental factors and participation.

---

<sup>3</sup> This section includes information from the report of the Washington Group on Disability Statistics to the 43<sup>rd</sup> session of the United Nations Statistical Commission (28 February-2 March 2012), and from the website of the Washington Group.

### **C. WHO/World Bank Model Disability Survey**

11. The WHO and the World Bank have recently promoted the development of a Model Disability Survey, with the objective of producing valid, reliable and relevant disability data to be used for disability policy at the national level. This initiative is a follow-up to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 31 of the CRPD mandates that ratifying States Parties “collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention”.

12. The main objective of the initiative is to produce a standardized survey instrument that enables:

(a) The collection of comprehensive and relevant information that helps countries construct a complete picture of disability, with particular relevance to addressing disability within both mainstream and disability specific policies;

(b) International comparisons; and

(c) National and global monitoring of the implementation of the CRPD.

13. An Expert Meeting on the Model Disability Survey was organized by the WHO in Geneva in December 2012, with the following objectives:

(a) To provide an overview of the process to develop a model disability survey;

(b) To review analysis of a sample of existing national disability surveys;

(c) To review and finalize the draft model disability survey questionnaire;

(d) To finalise the process for cognitive and pilot testing.

14. The discussion of the draft questionnaire at the expert meeting showed that a lot of work is still necessary to finalize the questionnaire. WHO plans to finalize and test the questionnaire in 2013 and make it available for use by countries in 2014.

### **III. COORDINATION OF ACTIVITIES**

15. As in other areas, the coordination of international initiatives in the area of health and disability statistics is essential to improve efficiency and optimize the use of available resources at the international and national level, but also to ensure general consistency of the methodologies developed and comparability of statistical outputs.

16. The partnership between the Budapest Initiative and the Washington Group on Disability Statistics can be considered as a good example of cooperation. Taking advantage of the experience and knowledge accumulated by the Washington Group, the Budapest Initiative was able to reach its objectives and produce with relatively limited resources a question set consistent with those developed by the Washington Group and tested by many countries.

17. In the case of the Model Disability Survey, promoted by the WHO and the World Bank, the draft questionnaire was designed making only limited use of the large amount of material (in terms of question sets and test results) developed over many years by the Washington Group and the Budapest Initiative. Several participants in the December 2012 WHO meeting expressed concern about the process in designing the questionnaire. It was stressed that if the questionnaire was built on the material already available from the Washington Group or the Budapest Initiative, then the efficiency of the process could have been improved. This would have saved resources and time for the development of the questionnaire, and would have ensured the comparability of the final results.

18. Furthermore, a number of participants in the WHO meeting noted that a disability survey could be conducted in their country only with the direct involvement of the national statistical office. However, there are no plans by WHO to involve the statistical community systematically in the programme, either through the Conference of European Statisticians, the United Nations Statistical Commission or otherwise.

**19. The CES Bureau discussed the coordination of existing initiatives in health and disability statistics.**

\* \* \* \* \*