

# UN ECONOMIC AND SOCIAL COMMISSION FOR ASIA AND THE PACIFIC

SPECA Project Working Group on Statistics  
Paris, 16 June 2006

ECE-ESCAP-SPECA/PWG-Statistics/2006/8

8 June 2006

## ESCAP/WHO Project on Improving Disability Statistics and Measurement in Support of the Biwako Millennium Framework and its Possible Follow-up Activities

### 1. Introduction

1. This report intends to briefly outline the recent ESCAP activities in the field of disability statistics which would be of significance for and have the potential of constituting synergies with the SPECA work programme in statistics.

2. In May 2002, in Otsu City, Japan, countries in the region adopted the Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific (BMF). This Framework reminded all Governments in Asia and the Pacific of the urgent need to establish national integrated information systems on disability and requested that such systems be developed by 2005. Countries were also urged to use common definitions and methodologies in developing their disability statistics.

3. In response to this call, in September 2003 ESCAP organized a regional workshop on Improving Disability Data for Policy Use, which inspired the design and formulation of the project entitled "Improving Disability Statistics and Measurement in Support of the Biwako Millennium Framework". The workshop introduced the new International Classification of Functioning, Disability and Health (ICF) into the region, and discussed national practices in disability data collection in many countries. The participants in the workshop agreed that national statistics on disability should rely on the ICF framework in order to improve the quality and comparability of data as well as their policy relevance.

4. One of the critical issues identified in the ESCAP region was the poor development of disability statistics. The BMF rightly noted that the lack of adequate and comparable data on disability and the experience of persons with disabilities have led to the neglect of disability issues and inadequate development of national plans and policies. The data collected in countries of the region did not reflect the full extent of disability prevalence nor did it give policy-makers a useful evidence base to draw on for designing disability policy.

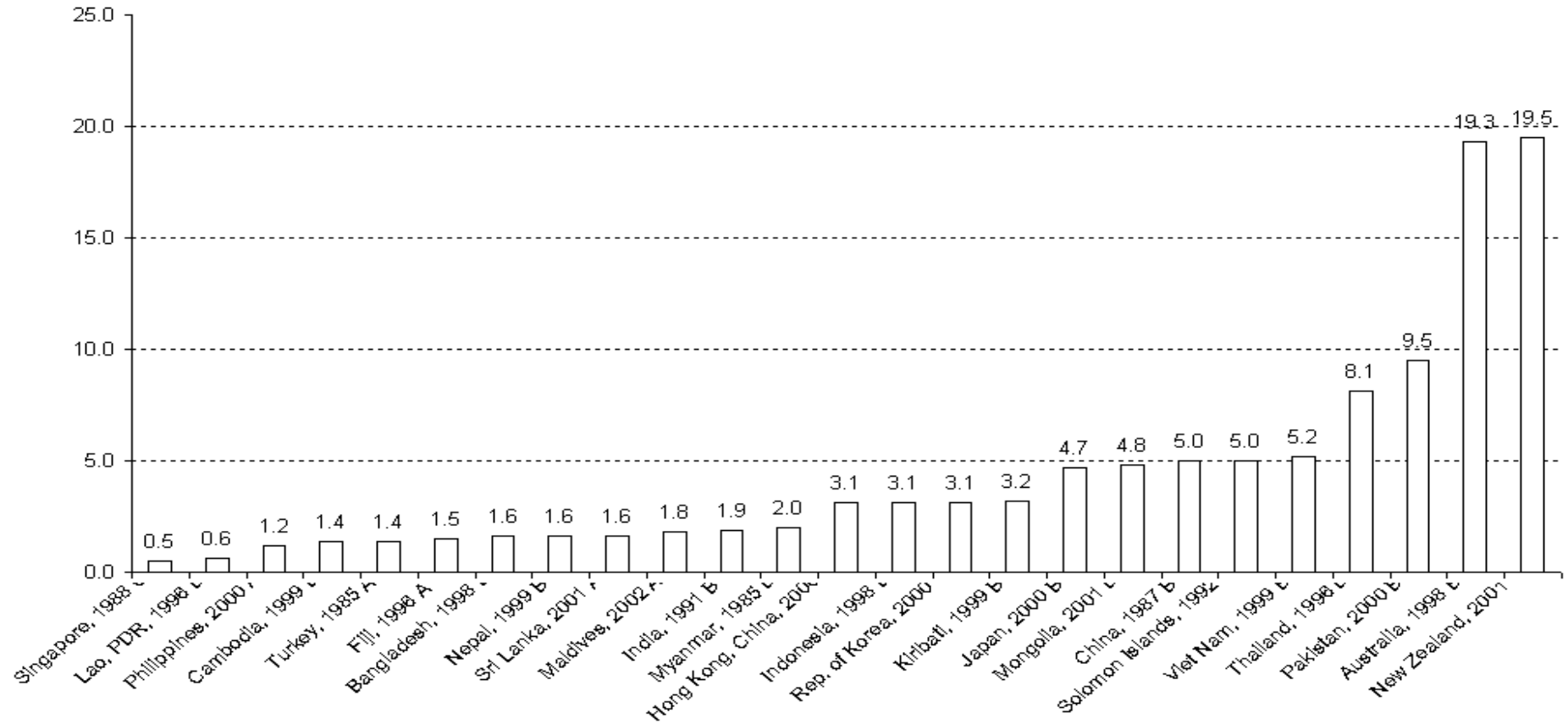
5. Furthermore, the lack of a common conceptual framework both nationally and internationally for all professionals working in disability impedes proper communication, rehabilitation and service intervention. **Chart 1**, which shows the reported disability prevalence rates, indicates that there is a serious problem with comparability in the region. Data collections for which a traditional approach to disability was applied resulted in extremely low estimates for disability prevalence, compared to more realistic figures in the cases where ICF was employed (e.g. the Australia and New Zealand surveys). This shows that traditional approaches to disability statistics are likely to under-report, or underestimate, the true prevalence of disability in a population. The BMF therefore recommended the implementation of the UN Guidelines and Principles for the Development of Disability Statistics and the use of WHO's ICF in the region. This classification, which was adopted by all WHO members in 2001, provided a unified and standard language and framework for the description of disability and health states. It has been accepted into the United Nations family of social and economic classifications and it incorporates the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.<sup>1</sup>

---

<sup>1</sup> See: Guidelines and Principles for the Development of Disability Statistics, UNSD (2001), at: [http://unstats.un.org/unsd/publication/SeriesY/SeriesY\\_10e.pdf](http://unstats.un.org/unsd/publication/SeriesY/SeriesY_10e.pdf)

**Chart 1**

Prevalence of disabled persons in Asian and Pacific countries (%)

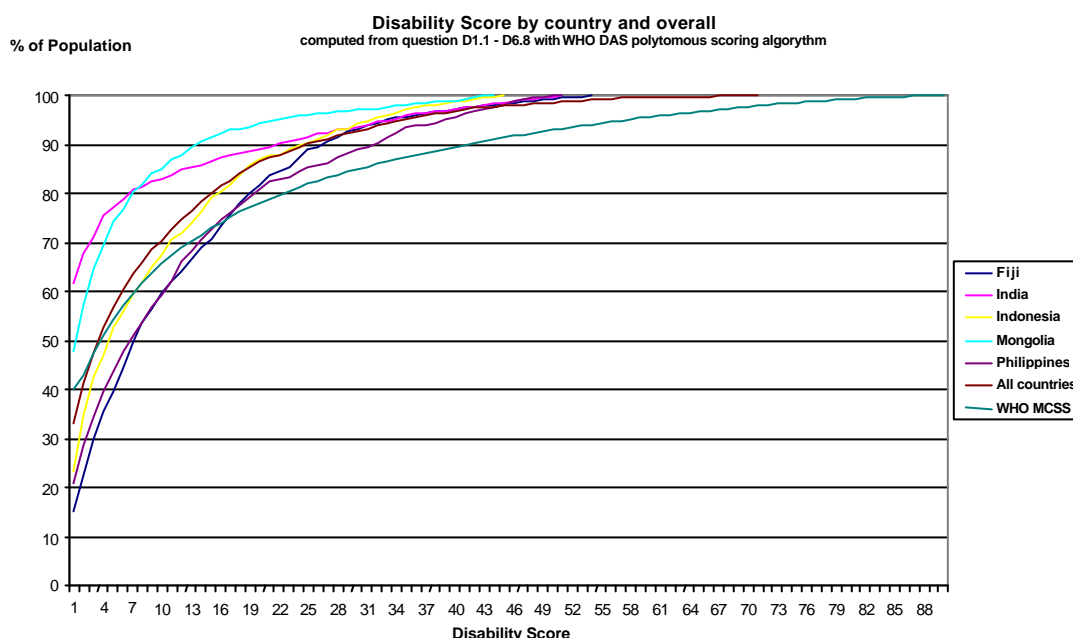


Source: United Nations DISTAT2

## 2. ICF-based Statistics on Disability

6. ICF-based concepts view disability as a function of the interaction between the physical and social environments a person faces as well as personal attributes. Disability is also viewed as a **dynamic** process in which a person's status can change over time and as a continuous phenomenon in which a person falls along a **continuum of disablement**. For example, the following graph shows the range of the World Health Organization Disability Assessment Schedule (WHO DAS II) Scores across populations in selected countries. ICF-based questions allow for the derivation of this "Disability Score Continuum", which is particularly useful for policy makers. In the continuum graph, there is no implicit threshold imposed that constitutes disablement, every person experiences some degree of health-related disablement in their lives. What is significant about this way of portraying disability prevalence is that the threshold decision represents a separate decision during analysis, and the data itself does not force or mandate a particular threshold be used. This is important because decisions about thresholds should be made by data users, not data producers. It may have different implications depending on the nature and purpose of the policy choice or assessment.

Graph 1



7. Following this ICF framework, any data collection on disability may assess both individual attributes and the characteristics of the environment that may affect an individual's participation. It allows for the dynamic nature and the full spectrum of disability. ICF-based statistics on disability are thus perceived to be more appropriate for policy making than earlier attempts at disability measurement, and will contribute to a better assessment of the process of equalizing opportunities for persons with disabilities. This approach will also lead to improved monitoring of the implementation of the BMF.

8. Another value-added benefit of adopting ICF to disability data collections is that it provides an international language and classification system for the concepts of disability. The absence of a common language, including understanding of the multidimensional concept of disability, is the principle cause of the lack of international comparability of disability statistics. Through the ICF, this essential need for a common understanding for terminology and definitions is achieved. Every country and region will be able to benefit from the integration into a common, scientific system for disability statistics and terminology. Moreover, ICF framework is compatible to WHO ICD-10 (shorthand for the International Classification of Diseases, Tenth Revision).

9. According to the experience of those countries that have integrated the ICF concepts into their data collections, more disabled persons are identified and the classification allows disability states to be described with clarity and precision. Furthermore, the use of standard concepts and definitions allow data to be compared across national sources and internationally, which is crucial to the monitoring of the implementation of the BMF in the region.



### 3. ESCAP/WHO Works on Disability Statistics

10. The ESCAP/WHO partnership project on improvement of disability statistics and measurement in support of the Biwako Millennium Framework, which is funded by the Government of the Republic of Korea, has advanced to the final stage. Its first phase (April 2004-March 2005) focused on creating a knowledge base and skills on the International Classification of Functioning, Disability and Health (ICF), while the ongoing second phase (April 2005-Sept 2006) aims to apply that knowledge to data collection. To achieve the objectives of improving disability statistics and measurement, the project conducted three major inter-related activities: Pilot Studies on disability surveys and question sets in five ESCAP countries, production of a *Disability Statistics Training Manual* directed at national statistics offices in the ESCAP region, and regional workshops organized in Bangkok by ESCAP in collaboration with the World Health Organization (WHO), the Australian Bureau of Statistics and the Australian Institute for Health and Welfare.

11. **Pilot Studies:** A draft questionnaire, which resulted from the third workshop mentioned below, was tested in pilot studies in Fiji, India, Indonesia, Mongolia and the Philippines. An expert from the Australian Bureau of Statistics was sent to Fiji and India to support national training of interviewers and fieldworkers. Analyses of the results from these studies is currently being done by WHO and ESCAP and will be presented at the fourth workshop in June, 2006, and included in the training manual.

12. The *Disability Statistics Training Manual*<sup>2</sup> is targeted towards national statistics offices and other statistics taking organizations in the Asia and Pacific region. This manual includes instruction on implementing the ICF into disability data collections in surveys, censuses, and administrative registries. The manual is designed for use in country training programmes in ICF implementation and developing data collection instruments that fit the needs of disability data users.

13. **The first workshop** in May 2004 had focused on training in the new International Classification of Functioning, Disability and Health (ICF). The workshop increased awareness among participants about the ICF and its uses in data collections, enabled each country team to draft a national

---

<sup>2</sup> The draft of training manual is available at: <http://www.unescap.org/stat/meet/widism4/index.asp>

action plan to utilize the ICF in their planned disability collections, and provided basic materials necessary to prepare a training manual on disability statistics for the second workshop.

14. **The second workshop** for improving disability statistics and measurement (Bangkok, 27-29 September 2004) was attended by official statisticians and disability policy experts from 19 countries and areas in the Asia-Pacific region as well as representatives from international organizations including the United Nations Statistics Division (UNSD). This workshop discussed practical issues in using the ICF for data collections. For example, the issue of standard question sets on disability to be tested at the country level was addressed as well as issues related to question formulation, testing and interviewing techniques. Participants were shown how to bring existing registers in line with the ICF and had the opportunity to report on progress of their respective national action plans in relation to upcoming data collections.

15. The workshop contributed further to deeper understanding of the ICF and the need to develop standard disability questions, which are in line with the ICF classification. Based on the discussions and country input, WHO and ESCAP, in consultation with UNSD and the Australian Bureau of Statistics, have developed two sets of questions suitable for testing in the region, i.e. one set for use in population censuses and another extended set for a disability module in a population-based sample survey. The workshop identified a number of countries which volunteered to test the proposed sets of disability questions. The testing required organizing country-level training on interview techniques in early 2005 with technical and financial support by WHO and ESCAP.

16. A small number of countries, (China, Fiji, India, Indonesia, Macao China, Mongolia and Philippines) attended **the third workshop** in May 2005. They were selected because they had agreed to the pilot tests for sets of disability questions proposed by WHO and ESCAP or because some of them planned to collect disability data from surveys in the near future. The workshop discussed the testing protocols and instruments prepared by the Secretariat and the implementation strategies and country-level work plans. At the same time, the participants had an opportunity to review the study protocols and disability question sets as well as other operational guidelines such as an 'Interviewer Guide' and 'Translation Guidelines'. Other important issues discussed covered sampling, quality control, data entry, etc. In addition, each country team developed a national action plan to implement the pre-testing activities in the months to come.

17. As a follow-up the third workshop and country pilot studies, ESCAP and WHO are organizing **the fourth workshop** (20-22 June 2006) to discuss recommendations for disability question sets for use in census and survey in Asia and the Pacific Region and finalize the training manual for disability statistics. Officials in the fields of disability statistics and policy from over 20 countries and international organizations have already agreed to participate. Three major expected accomplishments of this workshop are: (i) productive discussions and dissemination of the results analyses from the five pilot studies, (ii) inputs from countries and dissemination of the *Disability Statistics Training Manual*, and (iii) ideas-sharing and documentation of country needs for possible follow-up activities to the project.

18. **Table 1** shows the summary of the outcomes from the previous and forthcoming regional workshops on disability statistics.

Table 1: Summary of Regional Workshops on Disability Statistics

Workshop	Outcome
1. 24-28 May 2004	ICF and its uses in data collection introduced. National action plans to improve data collection on disability initiated. Preparation of a training manual on disability statistics started.
2. 27-29 September 2004	The training manual on practical issues in using ICF for data collection reviewed. A set of standard disability questions drafted for surveys and censuses, in line with ICF.

---

3.	3-4 2005	May	Questions and practical data collection issues further reviewed. Plans to test standard question sets at the country level developed. National action plans reviewed.
4	20-22	June 2006	To present and discuss the results for the field testing of disability question sets in five pilot countries presented and discussed; to discuss recommendations for disability question sets for use in census and surveys in ESCAP countries; to present the final version of Disability Statistics Training Manual and discuss its dissemination; and to discuss possible follow-up activities.

---

19. Parallel to the above activities, ESCAP as a member of Washington Group Steering Committee has carried out information, advocacy and coordination activities. It has used these opportunities to inform a variety of audiences about the project and the state of disability statistics in the region and to advocate the need to improve the disability information systems in accordance with the ICF framework. For example, ESCAP backstpped the national seminar on disability statistics organized by the General Statistical Office of Viet Nam, held in Hanoi on 29 and 30 June 2005. Furthermore, the activities and outcome related to disability statistics were also presented and well received at the Regional Workshop on Comprehensive National Plan of Action on Disability 19-20 October in Bangkok. This has strengthened coordination among stakeholders and facilitated their support of the project.

#### 4. Possible Follow-up Activities

20. **Coordinate with SIAP on their health and disability statistics training:** As mentioned, one of the main outputs of the project will be the *Disability Statistics Training Manual*. The manual will be disseminated on the ESCAP website and used for training by individual countries and The Statistical Institute for Asia and the Pacific (SIAP). SIAP could contribute by developing a training programme on disability statistics, to help align national data collection with ICF. A set of training materials for teaching disability statistics and ICF will be translated into national languages. Participants at the end of the two-year project will be able to facilitate and conduct national training courses for the improvement of disability information in their own countries.

21. **Introduce disability into the regional program of census recommendations:** Based on a comprehensive analysis of the country reports and data from the pilot studies, ESCAP intends to introduce disability into the regional program of census recommendations. The continued activities will support the 2010 World Population and Housing Census Programme. For the details of recent ESCAP activities in the field of population and housing censuses, which have the potential of constituting synergies with the SPECA work programme in statistics, please refer to ECE-ESCAP-SPECA/PWG-Statistics (2006)/7.

#### 5. Conclusions and Way Forward

22. The project made good headway by providing basic training in the ICF and international guidelines. A forum on disability statistics was formed and this will be used as an example for regional networking and country-specific recommendations on disability statistics. At the country level, another added value of this project was the identification of focal agencies in disability data collections.

23. The project contributes to the achievement of an inclusive, barrier-free and rights-based society for persons with disabilities by promoting the development of disability statistics. Improvement of disability statistics is one of the strategies recommended in the Biwako Millennium Framework for Action. Statisticians and health professionals in the disability field from selected countries in the region have been trained in using UN standards for collecting disability data and in the use of WHO's ICF. They have drawn up an implementation plan for disability data improvements in their countries and

they have been taught how to design questions to collect disability information. Pilot testing of questionnaires have been carried out in some countries and a forum for sharing experiences has been provided through ESCAP workshops.

24. SPECA countries and other stakeholders are welcome to discuss with ESCAP and WHO about the needs for implementing the ICF framework and disability statistics development outlined in this report. SPECA, ECE, and other stakeholders' views on the above project would help determine the level of interest for further projects which may include more pilot studies, and/or training and other implementation assistance.

-----