

**INFORMATION NOTE FOR THIRD MEETING  
OF THE WASHINGTON CITY GROUP  
ON DISABILITY STATISTICS  
(Brussels, 19-20 February 2004)**

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**SUMMARY**

The paper informs about the ongoing work on improving disability measurement in the United Nations Economic and Social Commission of Asia and the Pacific<sup>1</sup>(ESCAP). The member countries adopted in 2002 a regional framework for action, known as the Biwako Millennium Framework (BMF), to promote an inclusive, barrier-free and rights-based society for persons with disability. This has given ESCAP a strong mandate and obligation to work with governments and concerned stakeholders to improve disability statistics in the region. A first consultative meeting with member countries took place in 2003. As a result of the meeting, a two-year project was developed to be carried out in 2004-2005 by ESCAP, with the support of WHO and the UNSD. The project specifically aims at developing a common conceptual framework for measuring disability to improve quality and comparability of disability information and to facilitate achieving the goals of the BMF.

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<sup>1</sup>ESCAP is one of the United Nations five regional commissions. It is the largest of the commissions (58 member countries) and covers the most populous region of the world 3.8 billion, it is also the most diverse region and includes both some of the most and least developed countries.

## **Introduction**

1. The purpose of this paper is to inform the third meeting of the Washington City Group on Disability Statistics (WCG) of some ongoing work which is coordinated by ESCAP and which concerns its 58 Asian and Pacific member countries. In 2002, a High-Level Intergovernmental Meeting met in Japan and decided to adopt a regional framework for action that provides policy recommendations for Governments and concerned stakeholders to achieve an inclusive, barrier-free and rights-based society for persons with disabilities before the end of the decade. One of the critical issues identified is the poor development of disability statistics. The BMF rightly notes that the lack of adequate and comparable data on disability and the disabled persons has led to the neglect of disability issues and inadequate development of national plans and policies.

### **A. Situation analysis of disability statistics in the Asia-Pacific region**

2. The data collected in most countries of the region do not reflect the full extent of disability prevalence nor does it give policy-makers a useful evidence base to draw on for designing disability policy. For the majority of the countries in the region, the number of disabled persons is grossly underestimated with many reporting rates of less than 2 per cent of disabled which, according to WHO, is implausible. Furthermore, a common conceptual framework for all professionals working in disability is lacking in most countries, which impedes proper communication, rehabilitation and service intervention.

3. The inadequate state of disability information in the region is recognized in the BMF, which recommends the implementation of the UN Guidelines and Principles for the Development of Disability Statistics and the use of WHO's International Classification of Functioning, Disability and Health (ICF) in the region. With no reliable estimates of the number of disabled, types of disabilities or unmet needs for assistance, it is difficult to see how progress towards the stated goals in the BMF can be monitored. Moreover, without appropriate information on the demographic profiles of the disabled, where they live and what problems they experience, the prospects for developing and improving national plans and disability policies remain poor.

4. National disability information in most countries in Asia and the Pacific are mostly derived from a couple of questions included in the decennial censuses and from administrative type registers covering people with certain types of disability. It is estimated that the total number of disabled in the UNESCAP region is around 400 millions, which gives an idea about the immensity of the problem. As disabled persons often also are among the poorest of the poor, disability and poverty reduction in the region are closely related.

5. According to international experience, disability definitions that are based on ICF and the activity concept which focus on individuals' functioning are more relevant to policy and provide better coverage. Currently, only a handful of countries in the region apply the activity concept and use the ICF, the majority use an impairment approach to identify persons with disabilities. Hence, a generic question, such as, "Is there any person

in the household who is disabled?" is asked sometimes followed by one or two other questions to determine the kind of disability. The problems posed by this type of question regarding the interpretation of the term "disabled" and the sensitivities concerning disability are well known to result in under-reporting of the disabled population, particularly of those suffering from mental conditions and lesser physical impairments.

6. Because of lack of adequate statistical data on disability, policy makers often have to depend on administrative registers as the principal source. As these were not established for statistical purposes but for providing disability pensions or assistive tools, their coverage is incomplete and often limited to one type of disability. Moreover, essential socio-economic correlates of the disabled persons needed for well-informed policy are usually not part of the registers.

7. Finally, because most countries have used national standards and methodologies it is not really possible to compare data and draw conclusions about differences or similarities. Even time series comparisons within the same country often show implausible variations in disability between census rounds. The above state of affairs underlines the need for providing training in disability concepts and methodologies and in adapting international standards for national usage.

### **B. ESCAP forum for improving disability statistics**

8. In view of the need to develop national capacities in disability statistics, ESCAP held a four-day regional Workshop on Improving Disability Data for Policy Use in Bangkok, 23-26 September 2003. As part of the meeting preparation, the Statistics Division undertook a survey of the major disability sources in 16 countries in the region, which confirmed the conclusions in the above section. According to the unstandardized data, disability prevalence among the 16 countries, varied from less than one per cent to above 18, which clearly is epidemiologically implausible. The meeting confirmed that lack of knowledge and the use of inappropriate methods undoubtedly are the main reasons for this vast variation in disability prevalence among countries in the region.

9. The participants at the Workshop recommended that ESCAP establish a disability statistics forum to assist countries to promote the implementation of ICF and to develop a set of protocols based on good practice, for use in the development, collection, analysis and dissemination of disability data. WHO, UNSD, who participated in the workshop, were asked to provide input and support to the forum and its work. The meeting further recommended that the terms-of-reference of the forum should be to work out an action plan consisting of four components: a strategy for awareness building and promotion of ICF in countries; development of training tools in the use of international standards for producers of disability data; development and testing of a standard set of disability questions for a survey and/or census instrument; design of an implementation plan for the ICF strategy and its implications.

10. Following these recommendations ESCAP has developed a two-year project and together with participating countries will carry out the above action plan. The project will be funded by the Republic of Korea and will be launched in May 2004 with a five-day

meeting for participating countries. The target groups for the project are statisticians and health professionals involved in disability data collection. ESCAP's training branch for official statistics, the Statistical Institute for Asia and the Pacific (SIAP), will also be involved in developing the training materials and will ensure the sustainability by incorporating a course in disability statistics into its curriculum.

11. To the extent possible, during the two-year project time frame, empirical testing of the components would be carried out in a subset of participating countries. The objective of the action plan is that the four components would become a fully tested implementation framework with tools, ready to be applied and used by other countries in the region wanting to improve their disability data. The expected outcome for the participating countries is an improved disability information system which can provide reliable information and assist government in designing policies and determine the priority actions to take. Such a system is essential to promote integration of disabled people into society.

### **C. Special concerns with regards to WCG**

12. The stated objectives of the Washington City Group (WCG), to develop a common measure of disability or a set of measures to facilitate the comparison of data on disability across countries, are closely aligned with the goals of the Biwako Millennium Framework and with ESCAP's project and capacity building work in member countries. The strategy of the ESCAP project specifically includes the development and testing of some ICF-based disability measure, which can become a standard for participating countries to use in their data collections. The work of the WCG is therefore of direct relevance to the ESCAP project and offers opportunity for synergies for both sides, which should be explored through close cooperation and communication.

13. In formulating its strategic plan at the third meeting, the WCG is asked to take into consideration the work which has begun in the Asia-Pacific region and to give input to it by participating in the forum and sharing its experiences. Since part of the project will focus on the operationalization of disability concepts and piloting these in the countries, it could be an opportunity for applying the work of the WCG and empirically testing some of the measures developed. It would therefore be opportune if the methodological work on a standard measure or set of measures could be speeded up for preliminary testing in 2004.