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**PROGRAMME PLANNING AND EVALUATION: MONITORING AND EVALUATION:
REVIEW OF SELECTED PROJECTS IN THE THEMATIC AREA OF
POVERTY REDUCTION**

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**IMPROVING DISABILITY STATISTICS AND MEASUREMENT IN SUPPORT OF
THE BIWAKO MILLENNIUM FRAMEWORK**

Note by the secretariat

SUMMARY

The present document contains a report on the implementation of one of the secretariat's flagship projects, on improving disability statistics and measurement in support of the Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific. The project, funded by the Government of the Republic of Korea, aims at promoting the International Classification of Functioning, Disability and Health (ICF) as a unifying framework for disability data collection in the region, to improve the availability, quality, comparability and policy relevance of disability statistics. The present document describes the objectives and strategic activities of the project, its main accomplishments and remaining challenges. It also includes a proposal for possible extension of the project, through an integrated approach, to further increase both the national support and technical capacity for implementing the ICF approach, particularly through the upcoming 2010 global census round. The Committee may wish to review the progress of the project and provide views and guidance on the secretariat's initiative for future work.

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INTRODUCTION

1. For nearly two decades, ESCAP has stayed at the forefront in promoting an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific. In May 2002, 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, ushering in the Second Asian and Pacific Decade of Disabled Persons (2003-2012).
2. One of the critical issues identified in the Biwako Millennium Framework was the poor development of disability statistics in countries of the ESCAP region. The Framework 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 public policies. Countries were thus urged to use common definitions and methodologies, including the United Nations *Guidelines and Principles for the Development of Disability Statistics*,¹ in developing their disability statistics and to further step up efforts towards the inclusion of disability in the regular collection and dissemination of statistics as part of a national disability information system.
3. In response to the Biwako Millennium Framework, the regional Workshop on Improving Disability Data for Policy Use was held in Bangkok in September 2003. Statisticians, policymakers and representatives of disability associations participating in the Workshop agreed that the International Classification of Functioning, Disability and Health (ICF) provided a much-needed unifying framework for organizing a national disability information system. They recommended that ESCAP establish a disability statistics forum for interested countries in the region to promote the implementation of ICF, and develop a set of protocols based on best practices for use in the development, collection, analysis and dissemination of statistics on disability.
4. Based on the recommendations made at the Workshop, and as part of the overall ESCAP effort to promote better statistics in the region, the current project (2004-2006) on improvement of disability statistics and measurement in support of the Biwako Millennium Framework was developed and implemented by the ESCAP Statistics Division in collaboration with other national and international partners. As the project draws to an end, the present report reviews the objectives, strategy and activities of the project and assesses its impact and the remaining challenges. It also presents a proposal for possible extension of the project, through an integrated approach, to further increase both the national support and technical capacity for implementing the ICF approach, particularly through the upcoming 2010 global census round.

I. THE NEED FOR A UNIFIED REGIONAL APPROACH

5. Despite the urgent call in the Biwako Millennium Framework for better information on disability, the statistics in most countries of the region remain severely underdeveloped, which

¹ Statistics on Special Population Groups, Series Y, No. 10 (United Nations publication, Sales No.E.01.XVII.15).

seriously hampers attempts at assessing the prevalence and needs of people with disabilities, and designing and monitoring national policies on disability.

A. Common data problems

6. Very few countries collect information on disability regularly through censuses or surveys. The limited disability data that exist are mostly derived from a couple of questions included in decennial censuses, and do not reflect the full extent of the prevalence of disability or capture the true needs of the target population. For the majority of the countries in the region, the reported prevalence of disability is often below 2 per cent, which, according to assessments by the World Health Organization (WHO), is a gross underestimate.

7. For example, the 2004 United Nations Common Country Assessment for Afghanistan reported that estimates by WHO had predicted that between 20 and 40 per cent of the population suffered from a mental health condition, although “no reliable data are available”.² According to the 2005 assessment for Bangladesh, “national data on disability in Bangladesh are scarce and significant discrepancies are observed.”³

8. The often implausibly low disability prevalence rate obtained from censuses reflects the fact that, in the prevailing practice of disability data collection in the region, disability is usually defined as a medical or biological dysfunction, and includes only some of the most visible or severe forms of physical and mental impairments. For instance, the 2003 assessment for Kyrgyzstan recognized that the country was still using a traditional approach to disability measurement, which considered disability as an “illness” and gave a fragmented picture of disability in the country.⁴ With such a narrow approach, not only is the prevalence of disability usually grossly underestimated but there is also a serious lack of information on the experiences of people with disability and their need for specific care and services.

9. The comparability of existing disability statistics in the region also suffers tremendously from the wide variance in the definitions, standards and methodologies used across countries, making cross-country comparisons and regional monitoring extremely difficult, if not impossible. While the prevalence of disability in Australia was estimated to be 19.3 per cent for 1998, that for Cambodia was reported to be only 1.4 per cent in 1999, a difference resulting largely from the various definitions of disability used in the two countries.

² United Nations Country Team Afghanistan, *Common Country Assessment for the Islamic Republic of Afghanistan*, Kabul, 2004 (http://www.undp.org/rhap/Country_Office/CCA/), accessed 1 August 2006.

³ United Nations Country Team Bangladesh, *Common Country Assessment of Bangladesh*, Dhaka, 2005 (http://www.undp.org/rbap/Country_Office/CCA/), accessed 1 August 2006.

⁴ United Nations Country Team Kyrgyz Republic, *Common Country Assessment for the Kyrgyz Republic*, Bishkek, 2003 (http://www.undp.org/rbap/Country_Office/CCA/), accessed 1 August 2006.

B. ICF as a unifying framework

10. To improve the availability, quality, comparability and policy relevance of disability statistics in the region, it is therefore imperative to develop a unifying regional approach that addresses the conceptual and methodological issues directly. The *International Classification of Functioning, Disability and Health* of WHO provides such a framework.⁵

11. ICF is a multidimensional framework that treats disability along the functioning-health continuum as a dynamic process in which a person's status can change over time. It combines the medical and social perspectives in viewing disability and defines it as difficulties in functioning along three dimensions: impairments, activity limitations and participation restrictions. Impairment information alone thus presents only a partial picture of disability and impairments do not predict adequately the lived experience of people with disability.

12. In ICF, disability experience is recognized as a universal human experience and as a function of the interaction between the physical and social environments a person faces as well as the personal attributes. As an inclusive approach to disability measurement, ICF is fully compatible with the rights-based Biwako Millennium Framework approach.

13. In contrast to the restrictive, impairment-based categorization of disability, there is no explicit threshold imposed that constitutes "disability" in ICF: every person experiences some degree of health-related disablement in their lives. What is significant about this way of portraying the prevalence of disability is that the threshold for defining "disability" represents a separate decision by policymakers or other data users during analysis, and the data itself do not force or mandate a particular threshold to be used.

14. Following the ICF framework, data collected on disability may help to 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 perceived to be more appropriate for policymaking than traditional, categorical methods for disability measurement, and contribute to a better assessment of the process of equalizing opportunities for persons with disabilities. This approach provides a common ground for organizing all the information on disability into a national disability information system, and will thus lead to improved monitoring of the implementation of the Biwako Millennium Framework.

15. In the Asian and Pacific region, ICF has been implemented in Australia and New Zealand, while health professionals in Indonesia and Thailand have begun to use the ICF concept in some of their data collections. According to the experience of those countries that have done so, more disabled persons are identified and the classification allows disability states, activity and participation,

⁵ WHO, *International Classification of Functioning, Disability and Health* (Geneva, 2001).

and needs assessments to be described with clarity and precision. Furthermore, the use of standard concepts and definitions allows data to be compared across national sources and internationally.

C. Regional needs

16. Participants in the regional Workshop on Improving Disability Data for Policy Use held in 2003 recognized that, even though ICF has been accepted by WHO member countries and as part of the United Nations family of social and economic classifications, awareness of the framework among statisticians, health professionals and policymakers was low across this region. They also acknowledged that many national statistical offices in the region still lacked the technical capacity to carry out disability data collection following international standards or to properly analyse and disseminate the results, and that implementation of ICF required the development of standard protocols, especially recommended disability question sets, to be used through census and survey instruments.

II. PROJECT DESIGN AND IMPLEMENTATION

17. The current project is a direct response to the specific needs of the region. It is part of the overall efforts of ESCAP to implement the action required to achieve the Biwako Millennium Framework targets and to strengthen national capacity to produce better statistics. The project is closely linked to the work of ESCAP on promoting the achievement of the Millennium Development Goals in the region, particularly relating to poverty reduction and gender equality.

18. It is estimated that the total number of people with disabilities in the ESCAP region is around 400 million. People with disabilities are often among the poorest of the poor, and poor women and girls with disabilities often have to endure multiple burdens and severe discrimination. Better disability data help to enhance the public understanding of the relationship between disability, poverty and gender inequality, and promote the formulation and evaluation of proper public policies and programmes.

A. Objectives, strategy and activities

19. Under the overall goal of improving disability statistics in the region by applying the ICF framework in data collection and thereby supporting the implementation of the Biwako Millennium Framework, the project aims to promote the development, testing and implementation of a strategy for improved disability statistics in a core number of countries. The project is pursued through the following strategy and activities.

20. *Disability forum.* The project foresees the establishment of an ad hoc disability forum among a self-selected subset of member countries and associated member countries interested in improving their disability statistics. Through the forum, the project is designed to work out an action plan with four components: (a) a strategy for awareness-building and the promotion of ICF and the Biwako Millennium Framework among stakeholders; (b) the development and testing of a standard set of

disability questions for census or survey instruments; (c) design of an implementation plan for the ICF strategy and its implications; and (d) the development of ICF training tools for producers of disability data for national use.

21. *Core group with wider impact.* By focusing on a small number of countries, the project is expected to act as a catalyst for introducing ICF and promoting its implementation in the region. Statisticians and health professionals trained directly under the project form a critical mass of local experts with the ability to design and operationalize the ICF-based disability approach and produce more accurate and comparable disability profiles in their countries. These trained experts are further utilized as a local resource pool for wider regional initiatives and country-to-country technical cooperation.

22. *Priority countries.* The least developed countries and countries that plan to undertake disability data collection are given preference. Each country team consists of two experts with a mix of statistical skills and disability experience.

23. *Partnerships.* The Statistical Institute for Asia and the Pacific, WHO, the United Nations Statistics Division and the Washington Group on Disability Statistics are standing members of the project team, and the Australian Bureau of Statistics provides a resource person for key project activities. While SIAP focuses on developing and delivering training materials and training courses, WHO, the Washington Group and, to some extent, the United Nations Statistics Division are project partners in all technical issues and project activities. At a later stage, experts from project countries trained under the project (for example, the Philippines) also serve as resource persons to facilitate the activities.

24. *From regional to international.* Through the development of standard protocols for survey and census data collection in the region, the project contributes to the further refinement of international standards and recommendations on disability statistics. These standards, along with the action plan and training materials, are believed to have a wide influence among countries in the region in the adoption and implementation of ICF-based disability data collection and dissemination.

25. *Key activities.* In order to achieve the desired outputs, the project pursues the following activities:

(a) Conducting four regional workshops: (i) a five-day workshop to raise awareness of the ICF approach and other international standards and to develop national action plans; (ii) a three-day workshop to prepare for pilot testing of standard question sets for different data collection tools and related training and materials; (iii) a three-day workshop with pilot test countries to finalize plans and operational protocols; and (iv) a three-day workshop to review pilot test results and formulate regional recommendations and follow-up plans;

(b) Carrying out country pilot tests of standard question sets for censuses and surveys, and analysing the results;

(c) Developing a disability statistics training manual on the concepts, methodologies and implementation of ICF for disability data collection and dissemination.

B. Implementation of the project

26. Despite unexpected personnel changes on the ESCAP project team, all project activities have been implemented over the past two years.

27. *Workshops.* Over the course of the two-year project, ESCAP, in collaboration with WHO, organized four regional workshops designed to stimulate the successful development of a strategy for the implementation of the ICF framework in new and existing disability statistics systems in a diverse group of countries throughout the region.

28. The first Workshop for Improving Disability Statistics and Measurement, held in Bangkok in May 2004, was attended by disability experts and representatives of national statistical offices from 18 countries in the region, along with resource persons from the Australian Bureau of Statistics, the Australian Institute of Health and Welfare and WHO. Through presentations and group activities, participants were made more familiar with ICF concepts, best practices were disseminated, and strategic action plans were outlined for each participating national statistical offices for the implementation of ICF-based data collections.

29. The second Workshop, held in September 2004, was attended by many of the same participants as in the first Workshop, indicating a strong interest in sustaining efforts in the development of disability data into statistics systems in the region. Discussions on the formulation of standard question sets for disability modules in censuses or surveys created the basis for the pilot study questionnaires. In addition, presentations addressed practical issues in using ICF for data collections, such as issues related to testing, scheduling and interviewing techniques. Eleven country participants expressed interest in participating in the WHO/ESCAP pilot studies.

30. A small number of countries attended the third Workshop, held in Bangkok in May 2005. Participation was specifically focused on countries with disability data collection plans for the near future or a strong interest in participating in the WHO/ESCAP pilot studies. The participants had an opportunity to review the pilot study protocols and disability question sets as well as other pilot study operational guidelines, such as interviewing guidelines and guidelines for translation of the questionnaires prepared by ESCAP. Other important issues discussed included sampling and quality control. In addition, each country team developed a strategic plan to implement the pre-testing activities in the months that followed.

31. As a follow-up to the preceding activities, especially the pilot studies, ESCAP and WHO organized the fourth Workshop, held in Bangkok in June 2006 to discuss recommendations for disability question sets for use in censuses and surveys in the Asian and Pacific region and finalize the training manual on disability statistics. Officials in the fields of disability statistics and policy from over 20 countries and international organizations participated in discussions designed to establish a regional consensus on disability data collections in censuses and surveys based on the results analyses from the pilot studies in five countries. Productive discussions also addressed the draft disability statistics training manual and proposed regional training programmes to be implemented by SIAP. Conclusions from the Workshop helped to create a strong basis for a follow-up project for the continuation of advocacy and research work by ESCAP and its partners in this area. This includes the identification of specific country needs and the establishment of a working group network of experts with the objective of completing the process of finalizing standard question sets for use in censuses and surveys in the region.

32. *Pilot tests.* Ultimately, five member countries participated in the WHO/ESCAP pilot studies on disability questionnaires. With technical assistance from ESCAP, WHO and the Australian Bureau of Statistics, the national statistical offices in each country implemented three main studies for selected questions on disability. The three studies focused on the sensitivity and specificity, reliability and cognitive qualities of a comprehensive range of question phrasings and domains. The results and specific experiences of each national statistical office were disseminated through written reports and through presentations at the fourth Workshop in June 2006.

33. Comprehensive analysis of the outputs from each pilot study was conducted by experts from WHO prior to the fourth Workshop. The pilot studies produced many important results which helped to establish a provisional consensus by the participants, most notably the selection of the critical disability domains to be included in national census operations. Although it was established that further studies might be necessary in order to resolve a few remaining issues needed for establishing a more comprehensive set of recommendations on question sets for both censuses and surveys, the pilot tests provide the only current source of evidence in all three study areas for the internationally accepted range of question phrasings and approaches for disability measurement.

34. *Training manual.* During the execution of the other activities mentioned above, ESCAP and WHO have also overseen work on a disability statistics training manual. The United Nations *Guidelines and Principles for the Development of Disability Statistics* (2001) is the preceding essential resource for national and international organizations conducting disability statistics collections or analysis. However, the *Guidelines* were published shortly before the completion of the ICF framework of WHO. Therefore, the draft WHO/ESCAP Disability Statistics Training Manual answers the need for an information source updated for ICF. The manual has also been designed for

specific use as the main text in SIAP regional training courses on disability statistics, which are expected to begin in the fourth quarter of 2006.

35. The main topics reviewed in the manual provide instruction for developing disability statistics systems from the initial design phase and adaptation of surveys or census modules to particular data user needs, to reviewing testing and interviewing techniques, to data analyses and dissemination. The original version of the manual was written by an expert from the Australian Bureau of Statistics. After some preliminary editing by ESCAP and WHO, this initial draft was disseminated to participants in the fourth Workshop. Participants were given the opportunity to discuss their particular needs related to the manual and many representatives of countries and international organizations suggested possible additions. Currently, ESCAP, with assistance from contracted experts, is completing a final version of the manual to include recommendations of the Workshop and pilot study results. It is expected that the study will be published in late 2006.

36. *Working group.* As mentioned earlier, one of the important outcomes of the fourth Workshop was the creation of a working group of experts dedicated to the establishment of a comprehensive standard framework for disability statistics in censuses and surveys throughout the region. Several unresolved, technical issues were identified at the Workshop, which provides the working group with a general mandate. Continued discussions and analysis from the pilot study outputs, as well as possible future supplementary pilot tests, will be the main mode for the further development of a regional consensus. Country-specific analyses will be instigated and supported by the working group, which will simultaneously serve the purposes of complementing the results analysis conducted by WHO and providing an intraregional, cooperative mechanism for improving the technical capacity for data analysis in the participating countries. The working group officially comprises more than 30 distinguished representatives of national Governments, disabled persons' rights organizations and other international organizations, including United Nations agencies, WHO, the Washington Group on Disability Statistics and Handicap International.

III. REMAINING CHALLENGES AND OPPORTUNITIES

37. The Second Asian and Pacific Decade of Disabled Persons, 2003-2012, will conduct its critical mid-point assessment in 2007. ESCAP members and associate members will meet to assess the region's progress in implementing the Biwako Millennium Framework, and strategies for the second half of the Decade will be formulated. Despite the progress made in recent years, the persistent lack of adequate information on disability continues to hamper the effective monitoring and evaluation of the goals and target of the Biwako Millennium Framework.

38. The draft convention on the rights of persons with disabilities⁶ and the draft optional protocol of the United Nations stresses the importance of disability data for protecting human rights and for

⁶ A/AC.265/2006/4, annex II.

formulating and implementing proper policies. It urges all Governments to collect, disseminate and ensure the accessibility of appropriate information according to internationally accepted norms and through international cooperation.

39. The 2004-2006 flagship project has succeeded in creating interest and momentum among target countries for incorporating ICF into regular disability statistics data collection. Statisticians and health professionals from around 20 countries in the region have been intensively exposed to the ICF approach, and a small group of national experts are becoming important local resources for its implementation. Pilot tests have provided a valuable pool of empirical evidence based on which further tests and analyses could be carried out to facilitate the formulation of regional recommendations. A significant number of core countries are making preparations to include disability in the next census or in disability surveys.

40. However, countries participating in the fourth Workshop emphasized the strong need for the further promotion of the ICF approach in the region and for building national technical capacity for its implementation. In particular, country participants stressed the importance of increasing understanding of the benefits of ICF among all national stakeholders, including health professionals and policymakers, and the urgency of fully developing regional standards for collecting disability data from censuses and surveys that are comparable across countries. Such regional recommendations will contribute to the formulation and refinement of international standards on disability statistics.

41. Participants also emphasized the need for targeted training, technical assistance and advisory services in designing and implementing ICF-based data collection through censuses and surveys, and in analysing and disseminating data on disability.

42. The upcoming 2010 census round, in which the majority of ESCAP members and associate members will conduct population census activities within the next five years, presents a crucial chance to address the deficiencies of information on persons with disabilities. To improve the availability, quality and comparability of disability statistics in Asia and the Pacific, it is imperative to seize the opportunity provided by the upcoming global census round to promote a common regional approach to disability data collection through censuses and disability surveys, including post-census surveys.

IV. POSSIBLE FUTURE PROJECT

43. A new multi-year project on the improvement of disability statistics is being developed, building on the outputs and momentum of the current one. The new project will address the urgent need to provide technical support and develop recommendations that can influence national censuses and surveys (including post-census surveys) to be conducted in the next five years in many Asian and Pacific countries. The project is, therefore, not only in support of the Biwako Millennium

Framework, but also an integral component of a regional census programme to be fully developed by ESCAP for the region.

44. The project will be conducted through an integrated approach, combining pilot studies and regional recommendations with advocacy, training and country advisory services. It will build upon the achievements of the previous project and further guide and facilitate countries in the transition from a categorical and impairment-based disability measurement approach to a scalable and multidimensional approach in accordance with ICF for census and post-census surveys.

45. The project will again focus on selected countries with plans to include disability questions in upcoming censuses or surveys, and will cover all ESCAP high-priority country categories for technical cooperation. However, the project will have a wider influence on and implications for the region through its spill-over effects.

46. The project will be formulated based on country needs expressed explicitly by national statistical offices and health professionals at the fourth Workshop of the 2004-2006 project, and through consultations with WHO, the Washington Group on Disability Statistics, SIAP and the Emerging Social Issues Division of ESCAP. It will be pursued in close partnership with these international, regional and national partners (especially the Philippines).

47. Recognizing the gender dimension of the issue, attention will be given to ensuring that relevant gender concerns are addressed in the various aspects of the project, and that female professionals in the area of disability are properly represented in the project activities.

48. It is expected that the project will contribute to the common country assessments of participating countries and assist the United Nations Country Teams in their efforts to promote a rights-based and all-inclusive approach to identifying issues and monitoring and evaluating policies, giving particular attention to women and children with disabilities, ageing issues and the vulnerability of persons with disabilities to poverty.

49. The proposed new project will respond to the existing challenges and opportunities by expanding the scope of the 2004-2006 disability statistics project, linking it directly to the Regional Census Programme. It will promote the development of regional recommendations through wider pilot testing and result analysis, raise understanding of the ICF approach and build national technical capacity through targeted training, technical assistance and knowledge management.

50. Specific activities will include (a) additional pilot testing on proposed question sets for use in censuses and surveys responding to unresolved methodological issues revealed in previous pilot studies; (b) developing standard sets of questions for censuses and surveys through joint analyses, regional workshops and working group mechanisms; (c) organized subregional and in-country training on ICF standards to reach a broader range of national stakeholders; (d) technical assistance through advisory services and country-to-country cooperation; and (e) knowledge management

through a web-based knowledge centre, dissemination tools, including an interactive CD-ROM version of the training manual, and the regional network of national experts.

51. While the ESCAP Statistics Division will take responsibility for managing the project, activities will be implemented in close collaboration, as in previous years, with partners from WHO, the Washington Group on Disability Statistics, SIAP, the Philippines National Statistics Office, and internally with the Emerging Social Issues Division of ESCAP.

V. CONCLUSION

52. The efforts of the ESCAP Statistics Division in the area of disability statistics and measurement have been recognized and appreciated for their particular relevance to the region's needs and as a necessary component for accomplishing the commitments of countries to persons with disabilities under the Biwako Millennium Framework. The current project has aimed to promote and support the integration of ICF-based disability data collections into national statistical systems, while simultaneously promoting important developments, such as the formulation of common standards and country-to-country technical cooperation. Furthermore, in connection with the upcoming 2010 global census round, it is the intention of ESCAP to continue working in this area with a new project that adapts the strategy to more specific country needs as identified through the process of the current project.

53. The Committee may wish to review and evaluate the progress made under the current project and to provide guidance for the proposed future project on the improvement of disability statistics in the region.

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