

#### UNITED NATIONS SECRETARIAT

Department of Economic and Social Affairs Statistics Division October 2016 English only

# United Nations Regional Meeting on Disability Measurement and Statistics in support of the 2030 Agenda for Sustainable Development and the 2020 World Population and Housing Census Programme

26 – 28 July 2016 Bangkok, Thailand

Report

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### I. Background and Objectives of the Meeting

1. The United Nations Statistics Division (UNSD), in collaboration with the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), organized a Regional Meeting on Disability Measurement and Statistics in support of the 2030 Agenda for Sustainable Development and the 2020 World Population and Housing Census Programme. The Regional Meeting was held on 26-28 July 2016, in Bangkok, Thailand.

2. The objectives of the Regional Meeting were to compile national experiences, identify challenges faced and lessons learned in measuring disability from different sources of data, including population and housing censuses of the 2010 census round. It also provided an opportunity to initiate a discussion on the way forward towards the compilation of data on disability for monitoring of Sustainable Development Goals (SDGs) as well as the Incheon Strategy, a framework regarding persons with disabilities in the Asia and Pacific region. Furthermore, the Regional Meeting aimed at fostering intra-regional cooperation for enhanced national capacity in disability measurement and improvement of the quality of statistics on disability.

3. The Regional Meeting was attended by 43 participants of whom 26 represented 19 countries (Bangladesh, Bhutan, Cambodia, China, China (Hong Kong), Fiji, India, Indonesia, Iran (Islamic Republic of), Lao People's Democratic Republic, Malaysia, Mongolia, Myanmar, Nepal, Philippines, Singapore, Sri Lanka, Thailand, and Viet Nam). The Regional Meeting was also attended by 17 participants representing UNESCAP, UNSD, WHO, UNICEF and UNESCO. The list of participants is available in Annex 1.

## II. Organization of the Meeting

4. The Regional Meeting had seven plenary sessions and one small-group discussions session. The work programme for the Meeting is presented in Annex 2 and covers:

- (i) Disability-related SDG indicators for global monitoring; and (ii) Incheon Strategy to Make the Right Real for Persons with Disabilities in Asia and the Pacific
- 2) Disability statistics in the ESCAP region: An overview
- 3) Overview of ongoing international initiatives on standards for disability measurement
- 4) Overview of questions used in 2010 census round to identify persons with disabilities
- 5) Approaches used to measure disability through censuses: National experiences
- 6) Measurement of disability through sample surveys and administrative sources

- 7) Censuses, household sample surveys and administrative data as tools for generating data on disability for SDG indicators and Incheon Strategy monitoring framework: (i) strengths and weaknesses of the each data source; (ii) are there data gaps?
- 8) Strategies for meeting data needs for disability-related SDG indicators and for the Incheon Strategy Framework

5. Presentations made at the Regional Meeting are available at <u>http://unstats.un.org/unsd/demographic-social/meetings/2016/bangkok--disability-measurement-and-statistics/.</u>

III. Summary and Conclusions of the Meeting

Disability-related SDG indicators for global monitoring, and the Incheon Strategy to Make the Right Real for Persons with Disabilities in Asia and the Pacific (Session 2)

6. The session focused on data demands for evidence-based monitoring of progress towards inclusion of persons with disabilities in development programmes at the international level through the Sustainable Development Goals (SDGs) framework, as well as the regional level through the Incheon Strategy to Make the Right Real for Persons with Disabilities in Asia and the Pacific (hereafter, Incheon Strategy). Presentations provided some background information on the process for the development of the Sustainable Development Goals (SDGs), and on disability-related SDG indicators, on the overarching principle of data disaggregation for monitoring in order to ensure that no one is left behind, and also a mapping of the two frameworks to show their complementarity. It also highlighted some opportunities and challenges for countries to generate the required data for the SDG framework.

7. Participants recognized the enormous challenges to meet the demands of data arising from SDG monitoring and Incheon Strategy. In both development frameworks, disability data are needed as a base for disaggregation. During the discussions, it came to light that while the SDGs are already well known as a global action plan, many participants (representing national statistical offices) were not aware of the Incheon Strategy adopted by ESCAP countries which contains a large set of indicators for monitoring of its implementation, including those related to Goal 8 on improving the reliability and comparability of data.

## **Disability statistics in the ESCAP region: An overview (Session 3)**

8. ESCAP has made efforts to compile statistics on disability and to publish them in a report. The session was a review of the compiled statistics on disability in the region with emphasis on comparability of prevalence rates. The review showed that collection of

data on disability has increased over the time among countries in the region although there are still gaps in availability of data especially on disaggregation by characteristics of persons with disabilities. For example, while the majority of the countries in the region have produced data on the number of persons with disabilities and an associated prevalence rate, fewer have detailed labour statistics on persons with disabilities. Also, there are differences among countries, as well as variations within countries, in the availability of data for the Incheon Strategy indicators in areas of poverty, employment, education, accessibility, and health.

9. Available data show wide variation among countries in the prevalence of disability ranging from 1.0 % in Lao PDR to 18.5% in Australia. These cross-country variations are attributed to (i) differences in the conceptualization and definition of disability (medical vs. social model); (ii) differences in purposes of data collection; (iii) differences in methods of data collection (e.g. question, response scales); (iv) differences in data reference periods (periodicity of data collection); and (v) the interplay of these parameters which affect the comparability of the estimates. It was concluded that a common and consistent approach to data collection is required to improve the reliability and comparability of estimates among countries and even within countries when data are compiled from various sources.

# Ongoing international initiatives on standards for disability measurement (Session 4)

10. The World Health Organization (WHO) made a presentation about WHO's work on disability data as part of the WHO Global Disability Action Plan 2014-2021 which aims at strengthening the collection of disability data and research. Most of the presentation focused on the Model Disability Survey (MDS) that WHO is assisting countries to conduct. The MDS is based on a common questionnaire that has been developed by WHO to measure functioning from the perspective of capacity (the inherent or intrinsic feature of a person to do an action or execute a task "under the skin", and of performance (the doing of an action or execution of a task in the actual context of the individual "the lived experience"). The discussion that ensued showed that many participants were not clear about the differences between intrinsic "capacity" and "performance". Participants also expressed potential challenges in administering the MDS given the length and components of the questionnaire.

11. The presentation by UNICEF highlighted the need for reliable statistics on children with disabilities and also mentioned some of the challenges of obtaining such data. In order to address the need for comparable and reliable data, UNICEF in collaboration with the Washington Group on Disability Statistics has developed a module for measuring child disability among children 2 to 17 years of age (through two separate questionnaires: one for children aged 2 to 4 and another for children aged 5 to 17). The module aims to assess child functioning in light of barriers and supports to daily living

and social participation. The module uses the conceptual framework of the WHO International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), and relies on a functional approach to measuring disability. The module is used to assess speech and language, hearing, vision, learning (cognition and intellectual development), mobility and motor skills, emotions and behaviours.

# Questions used in 2010 census round to identify persons with disabilities (Session 5)

12. Information gathered as part of UNSD's monitoring of national implementation of World Population and Housing Census Programmes shows that the number of countries that have collected data on disability through the census has progressively increased over the census decades. For example, while 19 countries collected data on disability during the 1970 round, at least 112 did so during the 2010 round of censuses. The same information shows, however, that there is still considerable variation among countries in the questions used to measure disability and also in how existing guidelines are operationalized, including the Washington Group recommendations.

13. The type of questions used by countries in the Asian region fall into five broad categories: (i) list of impairments – Bangladesh, Bhutan, Cambodia, Nepal; (ii) a screener question about the presence of disabled household members followed by a list of impairments – India, Lao-DPR; (iii) a screener about household members with disabilities followed by list of impairments – Iran, Malaysia, Mongolia, Thailand; (iv) presence of list of impairments, medical conditions, functioning, participation – Korea, Rep of; and (v) Washington Group (WG) type of questions – Indonesia, Korea-DPR, Israel, Myanmar, Sri Lanka, State of Palestine, Qatar, Timor Leste, Turkey, Viet Nam. It should be noted that all the countries that used the WG-type questions made modifications of various types.

14. In addition to differences in the type of questions used, there are also observed differences in terminology used as well as the implied definition of disability that is being used. All these differences among countries in questions asked to measure disability have implications for cross-national comparability of data.

## Approaches used to measure disability: National experiences (Session 6 and 7)

15. The following countries made presentations about their measurement of disability through censuses (India [ORGI], Myanmar [Dept. of Population], Sri Lanka, Philippines, Fiji, Viet Nam, Indonesia, Mongolia, Iran, Malaysia); sample surveys (Cambodia, China [NBS], Bangladesh, China [Hong Kong]); and administrative sources (Thailand [Department of Empowerment of persons with Disabilities]).

16. Country presentations revealed that there is a wide variation among countries in country practices regarding collecting data on disability and also in the sources for generating data on disability. Presentations showed that for countries using population censuses to collect data on disability, there were differences in population coverage, including the age range and also inclusion and/or exclusion of those living in institutions and the homeless. Differences in how disability is measured are also evidenced by the variety and mixture of questions used. Many countries adopted the short set of Washington Group, but with various degrees of modifications, in terms of the number of items in the questions, the wordings, and response categories used. Hence, participants recognized the need for a clear definition of disability for measurement purposes, and the uniformity of terminology used. Participants also underscored the difficulties of understanding medical terms, as it may not be easy for interviewees to clearly understand the questions and give accurate information.

17. Participants recognized the complementarity of different data sources, namely, censuses, surveys and administrative sources, with their associated strengths and limitations for measuring disability, and underscored that the purposes of collecting data on disability should guide the choice of data source(s) and methodologies to be applied. In particular, it was pointed out repeatedly that census should not include complex questions on disability, which are more suitable for household sample surveys for indepth analysis on the situations of persons with disabilities. Furthermore, participants stressed that caution should be exercised when adding a disability module to other surveys because not all surveys are appropriately designed for disability measurement.

18. Other issues with implications for the quality of the data that participants drew attention to included: difficulties in getting respondents and the general public to cooperate and provide the information being asked for due to the stigma attached to disability; potential biases that might be introduced by using proxy respondents and by oral translation of questions in the field; difficulty in translating and interpreting into local languages of some disability terms during the interview; general lack of qualified enumerators to collect information on disability.

#### Censuses, household sample surveys and administrative data as tools for generating data on disability for SDG indicators and Incheon Strategy monitoring framework: (i) strengths and weaknesses of the each data source; (ii) are there data gaps? (Session 8)

19. Participants were divided into groups and discussed the strengths and weaknesses of the sources of data for measurement of disability, as well as the mandates for national, regional and global monitoring, including: the extent to which current national systems in the represented countries are sufficient for meeting data needs for national reporting and for Incheon Strategy and SDGs, how responsibilities for producing and disseminating data should be distributed by different government agencies and the required

coordination mechanism, and types of support that are required to strengthen the production and dissemination of data and statistics for national, regional and global monitoring.

20. Participants were of the view that existing data collection mechanisms are not adequate to meet the reporting demands for either the 2030 Development Agenda or the Incheon Strategy. It was also pointed that incomparability of data among different data sources is often a problem as there are different purposes for each source, but concluded that as statistics have to be compiled to meet specific data needs, comparability should not be of really high priority.

21. It was further pointed out that consultative mechanisms among stakeholders that exist in many countries need to be further strengthened (with the NSO leading the coordination) to improve the comparability of disability statistic and the efficiency of data collection and dissemination. Participants noted that at both regional and international levels, there is an urgent need to establish a coordination mechanism involving various stakeholders to fulfil the demands for regional and global monitoring of disability inclusive development.

22. Participants recognized that many countries in the region experience a dearth of experts on disability statistics. In order to further improve disability measurement, participants acknowledged a need to enhance the capacity of national offices through appropriate training as a priority. Participants noted that technical assistance in data collection, analysis and dissemination is required for national capacity building on disability statistics. In this connection, participants called for strengthening of communication between national and international stakeholders in order to identify training needs and how to implement the training.

23. Participants highlighted the need to use the ICF as an international standard but stressed that while international comparability of data on disability is desirable, national data needs take priority.

24. Participants further called for the promotion of the Incheon Strategy particularly to the data collection community and also for a review of WG recommended short set of disability questions. Some participants were of the view that the WG questions do not reflect country needs. Some also pointed out the approach of the WG does not include a time reference associated with functional difficulties.

# **Conclusions and way forward**

25. The concluding session gave a recap of what was presented and discussed during the meeting which showed that there are many demands for data and also many observed gaps in the data. There are also inconsistent and incomparable numbers based on different

definitions of disability which seem to have a disconnect from policy needs. To address these, it was suggested that what is required is to establish policy priorities and devote more resources, review existing infrastructure and experiences in order to establish what does and does not work.

26. At the country level, it was suggested that each country in the region have a national plan on disability statistics that is aligned with national, regional and global monitoring needs. Such plans should be consulted and agreed upon by all stakeholders and be part of the National Strategies for the Development of Statistics (NSDS). They should also be adequately funded and be backed by political and institutional support. Given the amount of the data that are required for monitoring and the likelihood that they come from different sectors of government, it was also suggested that each country establish an inter-ministerial group for statistical coordination with the lead coordination of the NSO.

27. At the regional and global levels, it was suggested to develop guidelines with harmonized measurement standards for data collection, dissemination and analysis encompassing censuses, surveys and administrative sources. The importance of IAEG-SDGs established under the auspices of the United Nations Statistical Commission for providing guidance especially on data disaggregation by disability status was recognized. It was also mentioned that regional and global organizations have a crucial role to play in terms of proving the required training and technical assistance to countries and also on outreach, advocacy and awareness-raising. Participants also raised the issue of whether there is a need for an international coordination mechanism on disability statistics given that there are multiple organizations and groups each promoting their tools and methodologies.

28. Looking ahead, regional level, ESCAP informed participants about planned events at which disability statistics and measurement could be discussed. These events include the High-level ministerial meeting in 2017 in Beijing which coincides with the mid-decade of and time for the establishment of baseline data for the Incheon Strategy. The region also plans to organize sub-regional workshops on SDG data at which the Incheon Strategy indicators will be part of the exercise of mapping of national, regional and global indicators. The meeting of the Committee on Statistics in December 2016 is another opportunity to discuss disability statistics in the ESCAP region.

#### **Annex 1. List of Participants**

#### BANGLADESH

Mr Md. Mir Hossain Deputy Secretary Government of Bangladesh

#### BHUTAN

Mr Tashi Dorjee Chief National Statistics Bureau

#### CAMBODIA

Mr Lay Chhan Deputy Director General National Institute of Statistics (NIS)

#### CHINA

Ms Lan Xu Senior Statistician National Bureau of Statistics

#### CHINA, HONG KONG

Ms Chui Fung Law Senior Statistician Social Statistics Branch (2) Census and Statistics Department

#### FIJI

Mr Epeli Waqavonovono Government Statistician Fiji Bureau of Statistics

#### INDIA

Mr Ram Pratap Deputy Director Government of India

Mr Ashok Kumar Samal Joint Director Office of Registrar General and Census Commissioner

#### INDONESIA

Mr Gantjang Amannullah Director of People Welfare Statistics BPS-Statistics Indonesia

#### IRAN (ISLAMIC REPUBLIC OF)

Mr Saeid Ghasemizadeh Tamar Senior Statistician Statistical Centre of Iran

#### LAO PEOPLE'S DEMOCRATIC REPUBLIC

Ms Phuangmala Rasasy Deputy Director of Research and Analysis Division Department of Social Statistics

#### MALAYSIA

Mr Keng Chuan Tan Director of Population and Demographic Statistics Division Department of Statistics Malaysia

#### MONGOLIA

Ms Urangoo Ganbaatar Population and Social Statistics Department National Statistical Office

#### **MYANMAR**

Ms Khin Win Nyunt Director Central Statistical Organization, Ministry of Planning and Finance Department

Ms Yin Yin Kyaing Deputy Director Department of populations, Ministry of Labour, Immigration and Population

#### NEPAL

Mr Nebin Lal Shrestha Deputy Director General Central Bureau of Statistics

#### PHILIPPINES

Ms Wilma Guillen Assistant National Statistician Social Sector Statistics Service Sectoral Statistics Office Philippines Statistics Authority

#### SINGAPORE

Mr Yap Yee Liong Senior Manager Singapore Department of Statistics **SRI LANKA** Mr Edirisuriya Mohottige Chandima De Seram Statistician Department of Census of Statistics

#### THAILAND

Ms Natpatson Nithiprapawat Chief of Social Statistics Coordination Group National Statistical Office

Ms Thansini Timsri Statistician National Statistical Office

Ms Arpaporn Amonthum Statistician National Statistical Office

Ms Pannee Pattanapradit Statistician National Statistical Office

Ms Tunlaya Amasuwan Social Development Officer, Professional level Department of Empowerment of persons with Disabilities (DEP) Ministry of Social Development and Human Security (MSDHS)

Ms Patcharapa Sintujariwat Computer Technical Officer Department of Empowerment of persons with Disabilities (DEP) Ministry of Social Development and Human Security (MSDHS)

### VIET NAM

Mr Chung Nguyen Dinh Deputy Director of the Social and Environmental Statistics Department General Statistical Office of Viet Nam (GSO)

#### UNITED NATIONS STATISTICS DIVISION

Ms Keiko Osaki-Tomita Chief Demographic and Social Statistics Branch United Nations Statistics Division

Ms Margaret Mbogoni Senior Statistician Demographic and Social Statistics Branch United Nations Statistics Division

#### **UNITED NATIONS CHILDREN'S FUND - UNICEF**

Ms Naira Avetisyan Programme Specialist (Children with Disabilities) East Asia and Pacific Regional Office URL: www.unicef.org/disabilities

#### WORLD HEALTH ORGANIZATION - WHO

Ms Alarcos Cieza Disability and Rehabilitation World Health Organization

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# Annex 2. Work programme

Time	Торіс		
<u>26 July 2016</u>			
9:00 - 9:30	Registration of participants		
9:30 - 10:00	Session 1 – Opening remarks - ESCAP - UNSD - Introduction of participants and administrative matters		
10:00 - 01:00	Session 2 – (i) Disability-related SDG indicators for global monitoring (ii) Incheon Strategy to Make the         Right Real for Persons with Disabilities in Asia and the Pacific – Session will cover (a) data needs for         disability-related SDG indicators for global monitoring, opportunities and constraints of existing data         sources, monitoring and reporting and their implications for frequency of data, and (b) an overview of how         disability has been mainstreamed in the Incheon Strategy         - Presentation by UNSD         - Presentation by ESCAP         - Discussion		
11:00 - 11:30	Coffee break		
11:30 - 12:30	<ul> <li>Session 3 – Disability statistics in the ESCAP region: An overview – A review of available statistics on disability in the region with emphasis on comparability of prevalence rates         <ul> <li>Presentation by ESCAP</li> <li>Discussion</li> </ul> </li> </ul>		
12:30 - 13:30	Lunch		
13:30 - 15:00	Session 4 – Overview of ongoing international initiatives on standards for disability measurement – The session will introduce on-going work at international level related to:         - WHO Model Disability Survey         - UNICEF Measuring Child Disability         - Discussion		
15:00 - 15:30	Coffee break		
15:30 – 17:00	Session 5 – Overview of questions used in 2010 census round to identify persons with disabilities – A presentation on disability questions used to measure disability during censuses of the 2010 round with emphasis on the ESCAP region - Presentation by UNSD - Discussion		
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9:00 – 10:30	Session 6 – Approaches used to measure disability through censuses: National experiences –         Presentations by countries on the questions used to measure disability, reasons for the choice of questions, testing of the questions, experience in how the questions worked in the field, use of proxy respondents, translation of questions, use of scaled response categories, and results obtained         - Country presentations: India (ORGI); Myanmar (Dept. of Population); Sri Lanka; Philippines; Fiji; Viet Nam; Indonesia; Mongolia; Iran; Malaysia         - Discussion		
10:30 - 11:00	Coffee break		
11:00 - 12:30	Session 6 – Approaches used to measure disability through censuses: National experiences (contd.) - Country presentations - Discussion		

Time	Торіс			
12:30 - 13:30	Lunch			
13:30 –15:00	<ul> <li>Session 7 – Measurement of disability through sample surveys and administrative sources – The session will cover the experiences of countries that have used sources other than the census to generate data on disability. It will cover topics on which data are available, sample size (if applicable), geographical level at which results are available, etc.</li> <li>Country presentations: Cambodia (DHS); China (NBS); Bangladesh (Household Income and Expenditure Survey); China (Hong Kong) (Survey on Persons with Disabilities and Chronic Diseases); Thailand (administrative records)</li> <li>Discussion</li> </ul>			
15:00 - 15:30	Coffee break			
15:30 - 17:00	Session 7 – Measurement of disability through sample surveys and administrative sources (contd.) - Discussion			
28 July 2016				
09:00 – 10:30	Session 8 – Censuses, household sample surveys and administrative data as tools for generating data on disability for SDG indicators and Incheon Strategy monitoring framework: (i) strengths and weaknesses of the each data source; (ii) are there data gaps? Small group discussion an overview of pros and cons as well as the adequacy of existing sources of data (censuses, household sample surveys and administrative sources) for generating data on disability for monitoring of SDG indicators and the Incheon Strategy. - Facilitators UNSD and ESCAP - Group discussions			
10:30 - 11:00	Coffee break			
11:00 - 12:30	Session 8 – Censuses, household sample surveys and administrative data as tools for generating data on disability for SDG indicators and Incheon Strategy monitoring framework: (i) strengths and weaknesses of the each data source; (ii) are there data gaps? (contd.) - Presentation of outcome of group discussions - Discussion			
12:30 - 13:30	Lunch			
13:30 - 15:00	Session 9 – Strategies for meeting data needs for disability-related SDG indicators and for the Incheon Strategy Framework – Session will cover steps to be taken to ensure generating reliable and quality data for on disability, including on how to address data gaps where they exist, further methodological development, if necessary, exploring ways to expand collection of statistical data and its dissemination, reaching out to users and stakeholders for political and financial support for statistical work, etc. - Facilitator: ESCAP - Discussion			
15:00 - 15:30	Coffee break			
15:30 - 16:00	Session 10 – Conclusions and way forward - Discussion Closing session - ESCAP - UNSD			