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**Department of Economic and Social Affairs
Statistics Division**

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**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**

Bridgetown, Barbados
5-6 September 2016

Report

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I. Background and objectives of the meeting

1. The United Nations Statistics Division (UNSD), in collaboration with the Caribbean Community Secretariat (CARICOM), and the Barbados Statistical Service, 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 Programme for the Caribbean countries. The Regional Meeting was held on 5-6 September 2016, in Bridgetown, Barbados.
2. The objectives of the Regional Meeting were to compile national experiences, identify challenges faced and lessons learned in measuring disability from 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). 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 brought together 26 participants of whom 15 were from Member States and Associate Members in the Caribbean region represented mainly by heads or senior staff of NSOs from Anguilla, Antigua and Barbuda, Bahamas, Barbados, Bermuda, Cayman Islands, Dominica, Grenada, Jamaica, Montserrat, St. Kitts and Nevis, St. Lucia, St. Vincent and the Grenadines, Suriname, and Turks and Caicos. The meeting was also attended by 11 participants representing UNSD, UNICEF, UNFPA, CARICOM Secretariat, and the Washington Group. The list of participants is available in Annex 1.

II. Opening Remarks

4. In his opening remarks, the Acting Director of the Barbados Statistical Service pointed out that the Regional Meeting was very timely to the countries in the region given the new data demands of the 2030 Agenda for Sustainable Development, that include also the development of indicators on disability. He further pointed out that measurement of disability through the 2020 round of the Population and Housing Census programme requires a consistent framework that would allow for the standardization and harmonisation of concepts used thereby facilitating the comparison of results over different time periods and across different countries. He also stressed that consistency in methodology is required for any meaningful comparison of results with estimates from previous censuses.
5. The Project Director, Regional Statistics, at the Caribbean Community Secretariat (CARICOM) pointed out that the area of statistics on persons with disabilities is an important one given its focus on one of the most vulnerable groups in society. She indicated that disability is a relatively new area of statistics to the region with the main initiative being its inclusion on the core questionnaire that was developed by Member countries under the Common Census Framework approach that was used for the CARICOM Regionally Coordinated Census strategy for the 2010 Census Round. The Project Director pointed out that a review of country practices showed that there was

appreciable adoption of the recommended questions on disability by Member countries resulting in some baseline information from the 2010 census. She informed the participants that the 2030 Agenda for Sustainable Development framework includes some indicators related to disability to which the CARICOM Region has provided some feedback. In conclusion, the Project Director stated that the recommendations coming out of the meeting would indicate what is feasible to be measured concretely, taking into account the capacity constraints of the countries.

6. The Chief of Social Statistics Section at the United Nations Statistics Division (UNSD) informed participants that sharing of current national practices for measuring disability helps to identify ways to improve official statistics on persons with disabilities, a population subgroup that has received attention in the 2030 Development Agenda, and for which countries will need high-quality, timely and reliable official statistics to ensure that they are properly counted and represented in official national statistics and not “left behind” in national development policies. She stressed that focusing on methods for disability measurement helps to raise awareness on statistical data requirements to meet the 2030 Development Agenda from a disability lens, and to create a platform to discuss institutional and data challenges National Statistical Systems may face in implementing the Agenda.

7. The UNSD representative pointed out that while national efforts to collect data on disability have improved over the years and more countries are including disability questions in their census, fundamental information to guide the formulation of disability inclusive development policies and programmes is still lacking in many countries; and where statistics exist, they often lack international comparability, as the concepts and methodologies used for data collection vary among countries. She informed participants that UNSD is addressing the issues of reconciling different disability measurements and improving coordination among agencies working on this topic, through an inter-agency and expert group on disability statistics, to be established by the UN Statistical Commission. She reaffirmed the commitment of UNSD to supporting countries in their statistical development and strengthening of institutions and technical capacities for the production of high-quality, relevant, reliable, timely and disaggregated data which respond to the Fundamental Principles of Official Statistics.

III. Organization of the Meeting

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

- 1) Disability-related SDG indicators for global monitoring
- 2) Overview of ongoing international initiatives on standards for disability measurement
- 3) Overview of questions used in 2010 census round to identify persons with disabilities

- 4) Approaches used to measure disability through censuses, surveys and administrative sources: National experiences
 - 5) Group discussions on production and use of statistics on disability in countries
 - 6) Conclusions and way forward
9. Presentations made at the Regional Meeting are available at <http://unstats.un.org/unsd/demographic-social/meetings/2016/bridgetown--disability-measurement-and-statistics/>.

IV. Summary and conclusions of the meeting

Disability-related SDG indicators for global monitoring

10. The session focused on data demands for evidence-based monitoring of progress towards inclusion of persons with disabilities in development programmes at the international through the Sustainable Development Goals (SDGs) framework, as well as some comments at the CARICOM regional level on the Sustainable Development Goals. The presentations by UNSD 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 highlighted some opportunities and challenges for countries to generate the required data for the SDG framework. Based on the presentation, participants recognized the enormous challenges that the countries in the region are likely to face in meeting the demands of data arising from SDGs monitoring.

11. The presentation by CARICOM provided some background information about suggestions of the Standing Committee of Caribbean Statisticians (SCCS) regarding activities pertaining to the production of a new set of goals, targets and indicators for the “beyond 2015 initiative. It was mentioned that the SCCS, took into consideration the special circumstances of CARICOM Member States and Associate Members as Small Island Developing States (SIDS) with generally inadequately resourced and overstretched national statistical systems that would be further impacted by the need for a vast range and quantity of data and statistics to monitor the Post 2015 Agenda, and urged the international Statistical Community to adopt a dual set - the full set comprising all the goals, all the targets and all the indicators, and a core set, comprising all the goals, all the targets and a selection of indicators manageable by CARICOM SIDS.

Ongoing international initiatives on standards for disability measurement

12. The session included presentations by the Washington Group on Disability Statistics (WG) and by UNSD. The presentation by the Washington Group gave some background on why the group, which is as a City Group under the aegis of the United

Nations Statistical Commission, was formed and on how it is organized. The presentation also provided information on the membership of the WG, as well as on annual meetings and consultations and workshops that have been organized since its inception. It also covered the tools that have been developed and tested by the group, including the WG short set, the extended set for adults, the module for measuring disability and functioning among children and youth, as well as ongoing collaborative work on a number of question sets that focus on the environment and participation, including the WG/UNICEF Module on Inclusive Education, and the module for inclusion on labor force surveys which is being developed in collaboration with ILO.

13. The UNSD made a presentation on the Division's Disability Statistics Programme in Support of the 2030 Agenda for Sustainable Development, highlighting its traditional mandate with regard to: (i) development of methodological standards, (ii) compilation of statistics, (iii) providing technical assistance to countries for national capacity building, and (iv) coordination at international level. The presentation provided a summary of broad activities of the programme based on the (i) 2020 World Population and Housing Census Programme which recognizes population and housing censuses as source of data designed to generate valuable statistics and indicators for assessing the situation of various special population groups, such as persons with disabilities, and (ii) 2030 Agenda for Sustainable Development which recognizes persons with disabilities as one of the vulnerable peoples and calls for their empowerment, and commits to enhance capacity-building support to developing countries to increase availability of high-quality, timely and reliable data disaggregated by disability. It was mentioned in the presentation that UNSD is organizing regional meetings on disability statistics and measurement and also, in collaboration with regional organizations, is planning data collection from countries. Participants were informed that the outcome of the two activities would feed into more detailed technical and operational international guidelines on the measurement of disability by the United Nations.

Questions used in 2010 census round to identify persons with disabilities

14. UNSD made two presentations on an overview of questions used to identify persons with disabilities during national censuses of the 2010 census round. The first presentation was based on information gathered as part of UNSD's monitoring of national implementation of World Population and Housing Census Programmes and showed 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.

15. The presentation shows differences among countries in the Caribbean region in the type of questions on disability with regard: the type of question(s) asked, the number of items included in the question(s), the number of questions asked, the use of a time reference, the use of (and wording of) a screener, response categories, and the type of respondent. The type of questions used by countries in the Caribbean region can be grouped into the following four broad categories: (i) A generic question on presence of long-standing (difficulty/problem) illness, disability or infirmity that limits carrying out data-to-day activities followed by Washington Group questions – Guyana, Montserrat, Trinidad and Tobago; (ii) a screener about whether household members have disabilities followed by list of impairments and WG question – Anguilla, Aruba, Cayman Is¹, Curacao, Sin Marteen, (iii) a screener about whether household members have disabilities followed by list of impairments and medical conditions – Bahamas, Barbados, Bermuda, and (iv) Washington Group questions – Anguilla, Antigua and Barbuda, Aruba, Belize, British Virgin Is, Curacao, Grenada, Guyana, Jamaica, Montserrat, Saint Lucia, Sin Marteen, St. Kitts and Nevis, Suriname, Trinidad and Tobago.

16. The second UNSD presentation uses questions on disability from some countries as examples to map the questions asked to the categories of the International Classification of Functioning and Disability (ICF) that they relate to. The examples in the analysis show that sometimes, countries including in their questions items that relate to medical conditions and not disability. The presentation also shows that sometimes, it is not easy to tell to which category of the ICF some of the items in the question relate to. The analysis also shows a lack of uniformity in terminology used, e.g. seeing, sight, vision. Where questions include an introductory phrase or question, there are observed differences in the terms use. Screening questions, when used, also show usage of different terminology among countries as well as the use of “yes/no” response categories in the screener that could lead to some persons with disability being screened out. There are also differences among countries in the response categories, including the use of “yes/no” and also of scaled response with differing categories of the degree of severity. The analysis also calls attention to how the following populations are covered: children, institutionalized population, and the homeless.

Approaches used to measure disability: National experiences

17. The following countries made presentations about their measurement of disability through censuses: Grenada, Antigua and Barbuda, Jamaica, Bahamas, Montserrat, Saint Lucia, St. Vincent and the Grenadines, Barbados, Dominica, Anguilla, Bermuda, Suriname, and Turks and Caicos.

¹ Did not ask a Washington Group question.

18. For the region, data on disability come mainly from population and housing censuses. Few countries in the region have collected data on disability through household surveys, and for those that have done so, there is a general lack of comparability between questions asked in the census and the survey. Countries indicated that, in general, they are challenged in the use of sample surveys to collect data on disability due mainly to small population bases and equally small numbers of identified persons with disabilities. For those that have used this source, the data are disseminated either at the country level or at some other high geographical level. Furthermore, administrative sources are not used to generate data on disability because there is fragmentation of such sources with a lack of linkage and harmonization of their content. Also, coverage of administrative sources may be limited to a particular population of interest. There was recognition among participating countries, however, that this source of data on disability should be strengthened and exploited.

19. The majority of countries in the region adopted the questions of the Washington Group as was recommended through the Common Census Framework approach that was used for the CARICOM Regionally Coordinated Census strategy for the 2010 Census Round. The presentations show, however, that in their application of the Washington Group recommended questions, all the countries made some type of modification to these questions. Modifications included introduction of a screening question, differences in the number of items in the questions, the wording of questions, and response categories used.

20. In their presentations, country talked about challenges that they experienced in collecting data through censuses. Some of the challenges reported included the fact that in a census situation, it is not feasible to provide the kind of intensive training that field workers would require in order to collect reliable information on such a specialized topic as disability. Furthermore, to be able to obtain accurate information would require more time to probe than is possible during a census. Countries also reported that some respondents were reluctant to report about their disability and that of others in their household due to the sensitive nature of this topic. Some reported that questions on disability are not always understood by respondents, thereby requiring explanations from interviewers, and also by interviewers in terms of what information was intended to be captured by the questions. Participants were of the view that these and other challenges may result a severe undercount of the population with disabilities. Consequently, it was highlighted that data on persons with disabilities that come from censuses should be used as a benchmark to further conduct more detailed specialized sample surveys for more accurate results.

Group discussions on production and uses of statistics in countries

21. Participants discussed in two groups: (i) the uses of statistics in their countries in terms of who the main users are, how the statistics are currently utilized and what mechanisms exist for promoting their utilization for policy purposes, and (ii) the

production of statistics in countries, identifying ways to strengthen national capacity to produce and utilize data on disability for monitoring progress towards inclusion of persons with disabilities in development programmes, how to better coordinate production of statistics on disability by relevant stakeholders in the national statistical system, and proposals for the next steps in developing this area of statistics (short and medium term).

22. Participants reported the main users of data on disability in the countries to be government agencies and organizations dealing with disability issues, as well as some international organizations. Some of the uses reported included implementation of programs, monitoring, adherence to and updating of Acts; policy formulation and planning; for advocacy purposes and interventions (access to funding and development of programs), and for compliance and reporting to international and regional agencies.

23. In terms of what mechanism exist for promoting utilization of data on disability for policy purposes the majority of countries reported that they have no formal mechanism. Only a couple of countries indicated that they have mechanisms in place for promoting utilization of data on disability for policy purposes and that their national statistical offices are also integrated into the monitoring process.

24. Regarding ways to strengthen national capacity to produce and utilize data on disability, participants indicated that while training for national statistical offices was necessary, such capacity building should also include other producers of statistics and cover concepts, definitions, and methodology. Other suggestions included training of all national stakeholders to understand the use of statistics in decision-making and policy development; sharing of best practices and knowledge transfer through south-south cooperation; and ensuring that persons with disabilities are an integral part of the planning and execution of the data collections and utilization.

25. Some of the proposals for next steps in developing disability statistics included training to build capacity in the countries; changing from the medical approach to the bio-psycho-social approach focusing on functioning, assessing data gaps, strengthening administrative datasets through harmonization and coordination with other sources.

Conclusions and way forward

26. The meeting expressed its appreciation to the Government of Barbados for its hospitality as well as to UNSD and the CARICOM Secretariat for organizing the event.

27. The meeting discussed disability in the context of the 2030 Sustainable Development Agenda and reviewed selected SDG global indicators explicitly referring to persons with disabilities. The meeting acknowledged that to fulfill new SDGs indicators requirements, an unprecedented amount of statistics will need to be produced by National

Statistical Systems, including on the status of persons with disabilities. The meeting also took note of the ongoing process in the CARICOM region to assess the relevance and measurability of the global indicators, in the context of the region, including a proposal to identify a core subset of these SDGs as a starting point given the capacity constraints.

28. The meeting took note of the specific challenges faced by SIDSs in terms of available data sources and capacity constraints within countries in measuring disability. Due to the small population sizes in countries in the region, sample based estimates give high margins of error and/or cannot be used for additional data disaggregation due to the limited number of detected occurrences that would also raise the issue of confidentiality if data were disseminated. The meeting stressed the importance of using multiple data sources to have a more comprehensive assessment of disability, by linking and triangulating across the key data sources - population and housing censuses, surveys and administrative data sources.

29. The meeting took note of the work of the Washington Group on Disability Statistics to develop harmonized methods to measure disability from population censuses. The meeting was reminded of the importance of: (a) avoiding the use of questions referring explicitly to disability; (b) avoiding using a screening question before the WG set of questions; (c) using a cutoff to identify persons with disabilities in the scale of severity to ensure this group is broad enough to capture more than just persons with severe impairments (probably already included in administrative records) but not too broad either, to avoid having most of the population classified as disabled. The meeting recognized the issue of cut-off points to be of such importance that more discussion is required on this topic.

30. The meeting took note of the disability statistics programme implemented by UNSD and its role in developing methodological standards, providing technical assistance and in coordinating international initiatives on disability statistics, to improve coherence among proposed methods to measure disability, and to ensure that these methods comply with/respond to data needed and relevant at the country level.

31. The meeting discussed how to link different data sources used for disability measurement (population censuses, household based surveys and administrative records). The use of population censuses as a baseline for identifying persons with disabilities, followed by a targeted survey was discussed as a way to gather more detailed information on their level of participation in all aspects of life and to respond to additional data needs of policymakers and other stakeholders.

32. Through the discussion on the questions used to measure disability during censuses of the 2010 round by countries in the region, participants identified a trend towards the use of a common set of questions on disability in the region. A review of questions asked showed, however, that there is still variation with regard to how the

questions are framed, the terminology used, the items included in the question(s), and how they relate to the ICF, the use of screeners, as well as having a mixture of functioning and medical conditions in questions. Participants highlighted that the design of questions to identify persons with disability should avoid the use of negative terminology in order to reduce stigmatization of reporting.

33. The meeting recognized that adaptation to national circumstances, rather than adoption, of international measures of disability may be necessary mainly based on outcomes of their testing and piloting in countries. Also, in the context of producing internationally comparable data on disability, participants raised the issue of how national priorities for measurement of disability can be harmonized with regional and international priorities.

34. Presentations on the experiences of countries showed that for the most part, there is strong reliance on censuses to collect data on disability with only a few countries getting these data through sample surveys and administrative data sources. It was further pointed out that use of the census to collect data on disability presents some challenges including, not being able to provide the necessary extensive training to field workers, overburdening of the census questionnaire, the reluctance of respondents to provide information, and the limited opportunity for detailed probing during interviews.

35. Participants also indicated an increased interest in the use of administrative sources for generating data on disability and noted that such sources could be used to get data on some disabilities which are difficult to investigate through censuses and surveys, e.g., on intellectual disabilities. It was recognized, however, that there is a general lack of comparability in the content and concepts used among different sources of administrative data within countries and also in the coverage of such sources.

Annex 1. List of Participants

ANGUILLA

Ms. ALLEYNE-FRANKLIN, Lori-Rae
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Anguilla Statistics Department

ANTIGUA AND BARBUDA

Mr. EDWARDS, Stachel Charlesworth
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BAHAMAS

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WASHING GROUP ON DISABILITY STATISTICS

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Associate Director for Science
National Center for Health Statistics, USA and
Chair, Washington Group on Disability Statistics

CONSULTANTS - UNITED NATIONS STATISTICS DIVISION

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Annex 2. Work programme

Time	Topic
<u>05 September 2016</u>	
9:00 – 9:30	<i>Registration of participants</i>
9:30 – 10:00	Session 1 – Opening remarks <ul style="list-style-type: none"> - Barbados Statistical Services - CARICOM - UNSD - Introduction of participants and administrative matters
10:00 – 11:00	Session 2 – Disability-related SDG indicators for global monitoring – This session will provide some background information on the process for the development of SDGs, and on disability-related SDG indicators for monitoring progress towards inclusion of persons with disabilities in development programmes. It will also highlight some opportunities and challenges for countries to generate the required data for the SDG framework <ul style="list-style-type: none"> - Presentation by UNSD - Presentation by CARICOM - Discussion - Chair: Carol Coy - Jamaica
11:00 – 11:30	<i>Coffee break</i>
11:30 – 12:30	Session 3 – Overview of ongoing international initiatives on standards for disability measurement – The session will introduce on-going work at international level related to: <ul style="list-style-type: none"> - Washington Group on Disability Statistics - UNSD - Discussion - Chair: Cornell Williams – St. Kitts and Nevis
12:30 – 13:30	<i>Lunch</i>
13:30 – 15:00	Session 4 – 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 Caribbean region - <ul style="list-style-type: none"> - Presentations by UNSD - Discussion - Chair: Iwan Sno – Suriname
<i>Coffee break</i>	
15:30 – 17:00	Session 5 – Approaches used to measure disability through censuses, surveys and administrative sources: 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. In the case of sample survey, it should also cover topics on which data are available, sample size, geographical level at which results are available, etc. <ul style="list-style-type: none"> - Country presentations: Grenada, Antigua and Barbuda, Jamaica, Bahamas - Discussion - Chair: Gatlin Roberts, St. Vincent and the Grenadines

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9:00 – 10:30	Session 5 – Approaches used to measure disability through censuses, surveys and administrative sources: National experiences (contd.) <ul style="list-style-type: none">- Country presentations: Montserrat, Saint Lucia, St Vincent and the Grenadines, Barbados, Dominica, Anguilla, Bermuda, Suriname, Turks and Caicos- Discussion- Chair: Stachel Edwards, Antigua and Barbuda
10:30 – 11:00	<i>Coffee break</i>
11:00 – 12:30	Session 6 – Group discussion – (1) Use of statistics in countries: (i) Who are the main users of disability-related statistics?, (ii) How are statistics on disability currently utilized in your country?, (iii) What mechanisms exist for promoting their utilization for policy purposes?; (2) Production of statistics in countries: (i) Identify ways to strengthen national capacity to produce and utilize data on disability for monitoring progress towards inclusion of persons with disabilities in development programmes, (ii) How can we better coordinate production of statistics on disability by relevant stakeholders in the NSS?, (iii) What do you propose as the next steps in developing this area of statistics (short and medium term)? <ul style="list-style-type: none">- Facilitators UNSD and CARICOM- Group discussions
12:30 – 13:30	<i>Lunch</i>
13:30 – 15:00	Session 6 – Group discussion (contd.) <ul style="list-style-type: none">- Presentation of group discussion summaries- Discussion
15:00 – 15:30	<i>Coffee break</i>
15:30 – 17:00	Session 7 – Conclusions and way forward <ul style="list-style-type: none">- Discussion Closing session <ul style="list-style-type: none">- CARICOM- UNSD