United Nations Statistics Division Population and Housing Census Programme: Focus on Measuring Disability

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Background

- At the beginning of each census round, ECOSOC adopts a resolution in support of conducting a population and housing census.

- UN Statistical Commission endorsed the draft Resolution on 2020 World Population and Housing Census Programme and submitted it to the Economic and Social Council of the United Nations for adoption.

- On 10 June 2015 ECOSOC adopted the Resolution.
Resolution

- Endorses the 2020 World Population and Housing Census Programme
- Urges each member state to conduct at least one population and housing censuses in the period 2015-2024
  - Based on international recommendations
  - Advance planning
  - Cost efficiency
  - Coverage
  - Timely dissemination
- Underscores the need for quality standards and assurance and compliance with the Fundamental Principles of Official Statistics
### 2010 Round

- Censuses conducted from 2005-2014 – 93% of world population

<table>
<thead>
<tr>
<th>Region</th>
<th>Countries/areas census conducted</th>
<th>Countries/areas census not conducted</th>
<th>Percent not conducted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>49</td>
<td>9</td>
<td>16</td>
</tr>
<tr>
<td>America, North</td>
<td>36</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>America, South</td>
<td>14</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asia</td>
<td>41</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Europe</td>
<td>49</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Oceania</td>
<td>25</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>214</td>
<td>21</td>
<td>9</td>
</tr>
</tbody>
</table>
2000 Round of censuses
2010 Round of censuses
Principles and recommendations

- United Nations Statistical Commission established in 1946
- Developing international standards for official statistics
- In the field of population and housing censuses
  - Population Census Methods (1949)
  - Principles and Recommendations for National Population Censuses (1958)
  - General Principles for a Housing Census (1958)
  - Principles and Recommendations for Population and Housing Censuses (1980)
  - Principles and Recommendations for Population and Housing Censuses, Revision 1 (1998)
  - Principles and Recommendations for Population and Housing Censuses, Revision 2 (2008)
  - Principles and Recommendations for Population and Housing Censuses, Revision 3 (2015)
UNSD Methodological framework

- **Principles and Recommendations, Revision 3**
  - Handbook on census management, Rev. 2
    - Guidelines on Use of Electronic Data Collection Technologies in Population and Housing Censuses
    - Handbook on Geospatial Infrastructure in Support of Census Activities
    - Handbook on Population and Housing Census Editing
Measuring disability and the Principles and Recommendations

- Disability as a topic was first introduced in Revision 1 (issued in 1998 for the 2000 round of censuses)
  - Provided guidance on
    - Use of standardized and internationally recognized terminology for defining and identifying the population with disabilities
    - Developing census questions
    - Possible outputs
  - Based on the *International Classification of Impairments, Disabilities and Handicaps (ICIDH/1980)* three dimensions
    - Impairment (organ or body dimension)
    - Disability (individual dimension)
    - Handicap (social dimension)
  - Following up on the International Seminar on Disability Measurement (2001) the UN Statistical Commission established the Washington Group on Disability Statistics
Measuring disability and the Principles and Recommendations

- *Principles and Recommendations, Revision 2* (2008, for the 2010 census round)
- Based on the *International Classification of Functioning, Disability and Health* (2001)
- Six essential domains
  - Four basic domains – walking, seeing, hearing, cognition
  - Two other domains (space permitting) – self-care, communication
- Additional domains (space permitting)
  - Upper body functioning of arms, hands and fingers
  - Psychological functioning
- Selection criteria for inclusion in the short set
  - Cross-population/cross cultural comparability
  - Suitability for self-reporting
  - Space on census form
  - Importance in terms of public health issues
Measuring disability and the Principles and Recommendations

- *Principles and Recommendations, Revision 2* (2008, for the 2010 census round)

- Each domain through a separate question
- Questions should be addressed to each household member
- Proxy respondent can be used to report for the family member who is incapacitated
- Scaled response categories can improve reporting of disability
Measuring disability and the Principles and Recommendations

- *Principles and Recommendations, Revision 3* (2015, for the 2020 census round)

- Comprehensive measure to determine disability
  - Four essential domains – walking, seeing, hearing, cognition
  - Two additional domains – self-care, communication

- Additional domains (space permitting)
  - Psychological functioning
  - ES domains – upper body (functioning of arms, hands and fingers) affect (anxiety and depression, pain and fatigue)

- Question have four response categories
  - No (meaning no difficulty at all)
  - Yes, some difficulty
  - Yes, a lot of difficulty
  - Cannot do (activity) at all

- Disability prevalence based on “a lot of difficulty” or “cannot do at all” response to questions
Collection of disability statistics from censuses by census rounds

- Collecting disability statistics by population and housing censuses steadily increased over time

### Countries that asked questions on disability in census

<table>
<thead>
<tr>
<th>Census round</th>
<th>Number of countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>1970</td>
<td>19</td>
</tr>
<tr>
<td>1980</td>
<td>36</td>
</tr>
<tr>
<td>1990</td>
<td>80</td>
</tr>
<tr>
<td>2000</td>
<td>103</td>
</tr>
<tr>
<td>2010</td>
<td>112*</td>
</tr>
</tbody>
</table>

* Based on questionnaires available to UNSD
<table>
<thead>
<tr>
<th></th>
<th>Total number of countries reviewed</th>
<th>Question on topic of disability</th>
<th>Use of Washington Group Short Set of Questions</th>
<th>Other questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total countries</td>
<td>141</td>
<td>112</td>
<td>45</td>
<td>68</td>
</tr>
<tr>
<td>Africa</td>
<td>33</td>
<td>29</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>America, North</td>
<td>25</td>
<td>25</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>America, South</td>
<td>7</td>
<td>6</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Asia</td>
<td>31</td>
<td>27</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Europe</td>
<td>24</td>
<td>11</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Oceania</td>
<td>22</td>
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<td>9</td>
<td>6</td>
</tr>
</tbody>
</table>
Collection of disability statistics – 2010 Census Round

- Based on a review of 124 census questionnaires (2010 round)
  - At least one question on the topic of disability was asked in 94 countries out of the 124 reviewed (76%)
  - Out of these 94 countries, 32 (34%) implemented the Washington Group recommendations
  - The four essential domains were investigated in almost all of these 32 countries - fewer countries investigated the additional domains of self-care (17), communication (14), upper body functioning (7) and psychological functioning (2)
Collection of disability statistics – 2010 Census Round

Experience on the use of proxy respondents

- In censuses, information is usually provided by a proxy respondent and this may negatively affect data quality, as the question on disability is subjective and dependent on the views of the respondent rather than that of the person with disabilities.
- Because of social stigma respondents are sensitive to talking about the disabilities in public - training of interviewers is important in gaining the trust and cooperation of respondents.
- It is particularly difficult to get to the correct degree of disability through proxy respondents.
Collection of disability statistics – 2010 Census Round

- Experience with translation of questions on disability into local languages
  - Many countries report challenges with regard to their experience in translating into different local languages
  - It is difficult to translate some words without distortion and in a manner that will not be regarded negatively thus affecting the credibility of the disability data obtained
  - Consultation with experts and associations dealing with disability issues is seen as important for appropriate wording that is not viewed negatively
Collection of disability statistics – 2010 Census Round

- Experience with use of scaled response categories
  - The same issue of subjectivity (proxy responses) affects disability question(s) that are of scaled response categories - respondents are trying to pick the scale categories that they feel are in line with the expectations of their immediate societal arrangements
  - Translation issues may arise and testing is necessary to get the right wordings for response categories in local languages
Collection of disability statistics – 2010 Census Round

- **Testing of questions on disability**

  - The majority of countries tested the questions on disability during the pre-testing and the piloting of the census.
  - Results and experience from testing helped in: rewording/redesigning questions in a way that did not cause sensitivity and avoided stigmatization; get the right translation in local languages; consult with experts and associations working on disability issues.
  - In a few countries, the Washington Group questions were tested in the pilot but not utilized in the actual enumeration.
Collection of disability statistics – 2010 Census Round

- Overall experience in how the questions on disability worked in the field

  - Disability questions are sensitive - problems arise when respondents do not want to cooperate or provide the right answer because of social stigma or when interviewers do not take the time to pause/probe where required in order to get the correct answers
  
  - Some interviewers do not ask questions as intended; training should be more rigorous and should emphasize the proper formulation/probing of questions in a standardized manner
Conclusions

Disability characteristics is a core topic in the previous and latest revisions of the international recommendations - countries should include questions on disability in the census, especially for countries in which alternative data sources are not available.

Discrepancies – often quite significant – between disability statistics obtained from the population and housing censuses, on one hand, and the specialized surveys, on the other, require further methodological research in identifying the underlying causes.

Due to the complexity of the collection of disability statistics in population and housing censuses, there is a need for substantial training of enumerators both for correctly understanding the questions, capturing responses and eliciting the trust and cooperation of respondents.