

# Revising the United Nations Census Recommendations on Disability

*Paper prepared for the First meeting of the Washington Group on Disability Statistics  
Washington, 18-20 February 2002*

**Margaret Mbogoni and Angela Me**  
**United Nations Statistics Division\***

## Summary

*The aim of the paper is to describe the issues that need to be considered in the revision of the section on disability included in the United Nations Principles and Recommendations for Population and Housing Censuses, Revision 1, issued in 1998. The discussion includes how the newly published International Classification of Functioning, Disability and Health (ICF) can be incorporated in the recommendations and how the recommendations could benefit from lessons learned in their implementation in the 2000 round of the censuses and from other studies performed to evaluate questions on disability. Issues that are suggested for consideration are: (i) new approaches in defining disability; (ii) a new list of types of disabilities based on the ICF; (iii) improvement of the wording and structure of questions to identify persons with disabilities; (iv) improvement of the dialogue between users and producers; and (v) the need to perform cognitive and quantitative testing of questions on disability. The paper also gives an overview of how countries have used the census to collect data on disability and it underlines advantages and disadvantages of its use highlighting its importance in the collection of information on persons with disabilities particularly in developing countries.*

---

\* The views presented in this paper are those of the authors and not necessarily those of the United Nations.

## Table of Content

1. Background: Disability and the Census .....	3
2. Review of Experiences in the Collection of Data on Disability ...	3
2.1 Defining Disability .....	4
2.2 Design of Questions .....	5
3. The United Nations Census Recommendations .....	5
4. The implementation of the Census Recommendations .....	8
5. Lessons Learned .....	9
5.1 Questionnaire Design .....	9
6. Revision of the Census Recommendations .....	12
6.1 Approach to the definition of Disability .....	12
6.2 List of ICF items to Describe types of Disabilities .....	12
6.3 Design of Questions .....	14
6.4 User/Producer Dialogue .....	16
6.5 Testing of Questions on Disability .....	17
7. How to Measure the Implementation of the Recommendations ..	17
8. Points for Discussion .....	18
9. Bibliography .....	19
Appendix 1 .....	21
Appendix 2 .....	23
Appendix 3 .....	24
Appendix 4 .....	27
Appendix 5 .....	29

## 1. Background: Disability and the Census

The census is the most important data collection activity of a country. Its primary objective is to count the population present or resident in the national borders and to collect basic social and economic characteristics. The census is used by many countries to collect data on persons with disabilities, particularly in developing countries, and for some countries such data have been collected through the census for a long time.<sup>1</sup> In some countries, the inclusion of a question on disability in the census is institutionalized and even dictated by law.

The review of the topic of disability by the United Nations in the Handbook of Population Census Methods (United Nations, 1959) attests to the role accorded the census as a method for collecting data on disability at the international level.<sup>1</sup>

Although data on disability collected through the census is limited in terms of accuracy and coverage, the census still provides many countries the only source of information on number of persons with disabilities and their social and economic characteristics. Unlike censuses, surveys can better measure the multidimensional aspects of disability using longer and more sophisticated statistical instruments. However, there are very few specialized surveys or multi-purpose surveys that are used on a regular basis to collect data on disability. Appendix 1 presents the advantages and limitations of using a census to collect data on disability.

## 2. Review of experiences in the collection of data on disability

Data and information available in the United Nations Disability Statistics Database, version 2 (DISTAT-2),<sup>2</sup> shows that countries that have included questions on disability on their population censuses has increased significantly in the past few decades. Appendix 2 lists the countries included in the database that have collected data on disability in their census according to the year and the prevalence rate obtained. Data from more recent censuses are not yet available for inclusion in the database.

There are substantial differences between the censuses in the rates of disability prevalence partly as a result of methodological differences with respect to:

- How disability is defined;

---

<sup>1</sup> For example, as early as in 1907 Egypt included a disability question in the census.

<sup>1</sup> In 1959 disability was presented as a topic of “national interest not recommended internationally” (United Nations, 1959).

<sup>2</sup> The United Nations Disability Statistics Database (DISTAT) is a global database including statistics, indicators and textual information from national data collected on disability issues.

- The design of questions used to identify the population with disabilities; and
- The type of disabilities included.

The high degree of variation in definitions of disability and of screening strategies used is also cited a major cause of the observed differences in the crude disability rates for 55 countries in the first version of DISTAT which was published in 1988 (United Nations, 1990 and Chamie, 1989).

## 2.1 Defining Disability

There is not much information in our collection on how disability was defined in national censuses. What is available shows that disability is defined differently in different countries. In general, the definition used sets the scope of who is targeted and determines the type of questions to be asked<sup>3</sup>.

Examples of definitions used in censuses include the following:

1. Canada, 1996 - *Disability refers to the limitation in the kind or amount of a person's activity because of a long-term physical condition, mental condition or health problem*
2. Aruba, 1991 - *Handicapped persons are persons with a physical or a mental disorder. The handicap is formed by the limitations of the personal abilities due to the disorder.*
3. Uganda, 1991 - *a disability is defined as any condition which prevents a person from living normal social and working life.*

As can be seen from these examples, disability in Canada was defined in terms of activity limitations, in Aruba in terms of impairments and in Uganda in terms of participation. The definitions used in national data collection activities may be influenced by the use of the data as well as cultural practices and perceptions in the countries concerned.

## 2.2 Design of questions

---

<sup>3</sup> In reality there are discrepancies in some countries between the definition of disability and the type of question(s) used. Sometimes, for example, countries use a definition based on the Disability dimension of the ICIDH, but ask impairment questions to identify the population with disabilities.

With regard to the questions used to identify the population with disabilities, there are differences in: (a) the type of questions used, i.e., whether impairment, activity limitations or participation based; (b) the wording of the questions with regard to terms used; and (c) the scope of the questions in terms of the number of disability items included.<sup>4</sup> The questions asked to identify the population with disabilities in censuses fall into three broad approaches:

Type 1 - A generic/general question on presence of a condition combined with items on participation and activity limitations. This typology has been used mainly in censuses in the Caribbean region.

Type 2 - A generic/general question on presence of the disabled or handicapped in the household followed by a list of impairments and/or disabilities. There are variations in the questions asked in this approach but typically, the question asks if there is a “disabled” or “handicapped” person in the household and if yes, what the type of disability is.

Type 3 - A checklist of impairments. This type of questions has been included in census questionnaires, particularly in Africa, Asia and South America, and refers to a checklist of specific types of impairments. For the most part, the questions provide a list of severe impairments from which respondents are required to choose.

Examples of questions related to the three types are reported in Appendix 3. As these examples show, there is a lack of uniformity in the questions used by countries to identify the population with disabilities. Countries that have used type 1 questions have higher prevalence rates than the other types. Countries that fall in type 3 have the lowest rates - e.g., India, 1981 (0.2%), Bahrain, 1991 (0.8%), and Nigeria, 1991 (0.5%).

### **3. The United Nations census recommendations**

The United Nations has, since the 1950s, developed international recommendations on population and housing censuses. The aim of these recommendations is to assist countries in planning and carrying out censuses and to guide them on the methods and content of their census. The last recommendations, contained in the *Principles and Recommendations for Population and Housing Censuses, Revision 1* (United Nations, 1998) include the topic of disability.

The recommendations provide guidance on how to define the population with disability, how to develop the questions to be used, and on possible tabulations. The recommendations for tabulations of data on disability emphasize the fact that countries

---

<sup>4</sup> The website of the United Nations Statistics Division - <http://esa.un.org/unsd/disability>- contains more detailed information on the methodologies used and the disability prevalence rates obtained.

need to go beyond tabulations that show only prevalence rates by gender and age and type of disability, to include also tabulations on key social and economic characteristics, such as marital status, school attendance, educational attainment, activity status, and occupation. The tabulations on the social and economic characteristics should have for comparison purpose both persons with and without disability.

These recommendations are in response to a number of issues, including the fact that:

- (a) The number of countries collecting data on disability in a census has grown dramatically in the past few decades, and for many countries, a census represents the only national source of information on disability.
- (b) There is lack of uniformity between countries and studies in how disability is conceptualized and measured; and
- (c) In general, countries have not used the ICIDH/ICF framework in defining the target population and also in the design of questions used to identify persons with disabilities.

Before the development of the census recommendations, there was a lack of international recommendations for population censuses or household surveys to guide the forming of appropriate concepts and measures in the collection and analysis of data on disability (Chamie, 1989). By developing the census recommendations on the topic of disability, the United Nations aimed at promoting the use of a standardized and internationally recognized terminology, based on the conceptual framework of the ICIDH, and to provide for common concepts and terminology to identify the population with disabilities. By recommending a common conceptual framework for collecting disability measurement, the United Nations aims to improve the presentation and ultimately utilization of the data collected.

The United Nations census recommendations recommend that countries use the disability<sup>5</sup> concept as defined in the ICIDH, to define the population with disabilities in census, and frame questions on disability in terms of activity limitations. Citing the space constraints on the census questionnaire, the United Nations recommends that for census purposes, countries focus only on one dimension of the ICIDH and use surveys to collect more detailed data on the other dimensions. The choice of focusing on disability and not impairment concept was based on the fact that disability-based terms, which focus on difficulties experienced in the performance of daily activities, are generally easier to understand, especially for the respondent, than those based on the impairment concept<sup>6</sup>. Therefore activity limitations questions tend to improve the reporting of disability and to

---

<sup>5</sup> In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being (WHO, 1980 and 1993).

<sup>6</sup> It would appear to be easier for persons to recognize difficulties they have doing things in daily life such as walking or dressing than to answer questions on a specific impairment condition, such as on impairments of internal organs.

include more people with mild, moderate as well as severe limitations in their performance of daily activities.

In the United Nations census recommendations, a person with disability is defined as “a person who is limited in the kind or amount of activities that he or she can do because of ongoing difficulties due to a long-term physical condition, mental condition or health problem” (United Nations, 1998). It is recommended that question used to identify the population with disabilities list the following broad categories based on the ICIDH disability concept:

- (1) Seeing difficulties (even with glasses, if worn);
- (2) Hearing difficulties (even with hearing aid, if used);
- (3) Speaking difficulties (talking);
- (4) Moving/mobility difficulties (walking, climbing stairs, standing);
- (5) Body movement difficulties (reaching, crouching, kneeling);
- (6) Gripping/holding difficulties (using fingers to grip or handle objects);
- (7) Learning difficulties (intellectual difficulties, retardation);
- (8) Behavioural difficulties (psychological, emotional problems);
- (9) Personal care difficulties (bathing, dressing, feeding);
- (10) Others (specify).

The disability items in the census recommendations were developed taking into account the experience of countries in items investigated in national studies that used the ICIDH as a guide to formulate questions. A review of data of data in DISTAT showed that some categories of disability were more commonly investigated than others (Chamie, 1989). Based on this finding, a short list of the most commonly investigated categories was developed and this list was informative in the development of the census recommendations.

The recommendations stress the need to ask every respondent each of the categories on the list<sup>7</sup> and not to treat the items only as a list of disabilities for the people who answered yes to a generic screening question. This was to avoid the problems experienced in many countries in the use of generic questions<sup>8</sup> and to properly report multiple disabilities.

Although the census recommendations were developed when the ICF revision process was still in its infancy, it should be noted that the recommended categories based on the ICIDH, are still included in the ICF. However, the items on seeing, hearing, and

---

<sup>7</sup> “The question used to identify persons with disability should list broad categories of disabilities so that each person can check the presence or absence of each type of disability” (United Nations, 1998)

<sup>8</sup> These problems are related to the fact that respondents may look at disability as a stigma and/or as only related to the most severe impairments. As soon as they realized that the question asked is in relation to disability, they may not think about the wording used (that could be related to activity limitations) and they relate their answer only to what they think is disability.

behaviour are now part of body functions rather than activities in the ICF. In methodological guidelines developed during the final stages of the ICF development process, the United Nations recommends that countries adapt the ICF in their data on disability collection activities (United Nations, forthcoming).

To increase the policy relevance and utilization of the data on disability, the census recommendations urge countries to go beyond presentation of data that is limited to simple tabulations of the population with disabilities to include also tabulations on the living conditions of persons with disabilities, including on (a) place of residence; (b) type of household; (c) marital status; (d) cause of disability; (e) educational characteristics; and (f) economic characteristics. To assess the principles of equality and full participation, tabulations on socio-economic characteristics should include also persons without disabilities for comparison purposes.

#### 4. The implementation of the census recommendations

To assess the extent to which the countries have implemented the census recommendations, we have reviewed some of the questions on disability used in countries that had their census during the 2000 round of censuses (1995-2004)<sup>9</sup>. Appendix 4 reports the experience of these countries in terms of the ICIDH/ICF concept used in the question to identify the persons with disabilities and the categories used to describe the types of disability.

The limited experience we have of questions used or to be used in the 2000 round of censuses shows a mixed picture. In the countries of South America and Africa, except in South Africa and to a limited extent in Uganda, the census recommendations have not been implemented: the impairment concept is used and the questions still include severe types of impairments. In the Caribbean countries, except in Jamaica and Saint Lucia, the questions refer to activity limitations and on the whole the categories included in the questions are similar to those recommended by the United Nations.

We note that only two of the reviewed questions have included the category of personal care *difficulties in bathing, dressing, and feeding*. Only Belize in the 2000 census fully implemented the recommended use of the list of categories as a checklist<sup>10</sup>. None of the other reviewed countries used this approach<sup>11</sup>. It seems that countries are more inclined to use generic questions to identify persons with disabilities rather than a checklist of

---

<sup>9</sup> We analyzed only those countries from which we had we had information on the disability questions used in the census.

<sup>10</sup> "Do you/Does ... have problems with any of the following? A. Sight difficulties (even with glasses, if worn), b. Hearing difficulties (even with hearing aid, if used), c. Speaking difficulties (speaking), d. Moving/mobility difficulties, e. Body movement difficulties, f. Gripping/holding difficulties, e.g. Learning difficulties (intellectual difficulties, retardation).

<sup>11</sup> This may be because of the additional resources that come with the checklist approach in terms of space, interview time and data processing time. If the respondent is requested to answer yes/no to each of the items in the list the disability question becomes a series of n questions that should be applied to each respondent.

activities. One of the objectives in recommending the checklist approach was to have a full count of multiple disabilities. Using a generic question, countries had different ways of handling multiple disabilities<sup>12</sup>.

More evidence is needed to give a better assessment of the extent of implementation of the United Nations census recommendations on disability but looking at the type of questions used in the reviewed countries, we can say that the census recommendations have not been implemented as much as it was hoped. 50% of the countries we analysed used an impairment approach instead of the suggested activity limitation approach. Nevertheless, we think that the recommendations had some impact on how disability has been approached in censuses. 5 of the 21 reviewed countries fully adopted the recommendations in terms of approach and categories used improving the questions adopted in the previous census<sup>13</sup>. One country, did not follow completely the recommendations in the approach used to identify persons with disabilities, but adopted the list of categories. It may take time before all countries introduce in their census new approaches to disability as suggested in the recommendations, but some experiences have showed that the recommendations have helped in the adoption of the ICIDH/ICF and we are confident that they will continue to do so in the future.

## **5. Lessons learned**

### **5.1 Questionnaire design**

Some studies have been carried out in developed countries to assess the quality of census questions used to identify disability in terms of validity and reliability and the impact of different approaches and terminology in the prevalence rates. For example, Australia (Davis and Gligora, 2001) performed cognitive and consistency testing in 1997 and 1998 on different types of questions to include in the 2001 census<sup>14</sup>. The British Office for National Statistics (1998) critically reviewed questions used to identify persons with disability in surveys and censuses and Statistics Canada did a qualitative and quantitative evaluation of questions to improve the methods used to filter disability in the census (Langlois 2001)<sup>15 16</sup>.

---

<sup>12</sup> Some of the countries give a maximum of two or three types of disabilities that an individual can choose, some include a specific item “multiple disabilities”, others leave the individual free to choose all the types that apply.

<sup>13</sup> For countries such as Bahamas and Belize for example questions on disability used in the 1990 round of census were based on impairments.

<sup>14</sup> Three types of census questions were tested against how well and how consistently the population having and not having a disability match the population that would have been identified by the Survey of Disability, Ageing and Carers. Based on the data obtained by the tests, the Census Disability Advisory Group decided not to include any disability question in the 2001 census since none of the questions gave the targeted 80% rate of matched cases.

<sup>15</sup> Previously, Canada compared responses to the disability questions on the 1986 census data to those from the 1986 Canadian Health and Activity Limitations Survey (HALS) (Furrie, 1989).

A major problem highlighted in these studies is the difficulty of using a few questions to identify the whole continuum of persons with disabilities, from those who have very severe types of disability to those who have more mild disabilities. Also, results of these studies show that terms such as *long-term, disability, handicap* are perceived by the respondents as negative terms linked to very severe types of disabilities and this is likely to lead to underreporting of mild disabilities (Langlois 2001). The phrase *being limited* is also considered negative and it is better if the term “limitation” refers to *having an activity limitation* rather than to *being limited*.

In both Canada and Australia, use of scaled responses was found to improve the respondents’ ability to report having disabilities. These findings are confirmed by other researchers who have argued that disability status is a complex phenomenon that involves multiple dimensions of health and severity. If the respondent can not choose among these multiple dimensions, he/she is likely to misreport his/her disability status (Mathiowetz, 2000 and 2001). It is argued that disability is not a yes or no phenomenon but rather a status that varies on a continuum in terms of intensity (mild disability) and time (cyclical disabilities). Alternatives such as *Yes sometimes, Yes often, No*<sup>17</sup> (Canada) or *None, A little, A lot*<sup>18</sup> (Australia) have proven to give better results.

There are many lessons that can be learned from the studies reported above but since they were all be conducted in developed countries, there is the need to understand the impact of cultural attitudes on the design and wording of questions in developing countries<sup>19</sup>. It is not clear if the results obtained in countries such as Canada, the U.K., U.S.A., and Australia would have the same results in countries with different cultures and different views of disability.

A statistical analysis of the relationships between different question designs used and prevalence rates obtained in developing countries was performed on data available in DISTAT-2 with the idea of measuring the performance of different typologies of questions used to identify persons with disabilities (Me and Mbogoni, 2001)<sup>20</sup> in less developed countries. According to this analysis, two characteristics of questions designed to identify persons with disabilities in a census have a significant impact on the reporting of disability:

---

<sup>16</sup> The U.S. Bureau of the Census also performed validity and reliability studies for the disability questions included in the 1990 census (McNeil, 1993).

<sup>17</sup> These are response items related to the question: “Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing similar activities?”

<sup>18</sup> These are response items related to the question: “How much difficulty does the person have in doing everyday activities such as eating, showering or dressing?”

<sup>19</sup> Some studies have been carried out on survey questions. For example studies on validity, sensitivity and reliability of survey screening questions have been performed in some developing countries in relation to child disability (Durkin, 2001).

<sup>20</sup> The analysis gives useful information on the impact of different question characteristics, however, it is biased by a heavy use of impairment-based questions and low prevalence rates.

- Whom the question is addressed to, i.e., person level or household level question. A question addressed to household members individually (person level question) such as, *Is (name) limited in ...* is associated with higher reporting of disability than a single question asked for all the household (household level question), such as, *Is there anyone in this household who is limited ....* The analysis shows that a person level question is 5 times as likely to have a high prevalence<sup>21</sup> rate as a household level question. This finding is confirmed by Jennifer Hess et al. (2001) where person-level questions were compared to household-level questions in a study carried out in the U.S. The data show that a person-level question identifies more people with functional limitations than a household-level question. However, the study also reports that household-level questions produce more reliable data than the person-level approach and in a shorter interview time.
- List or not list based question. Questions based on a specific list of disabilities seem to have higher reporting of disability than questions based on a generic question. Questions based on a list are 3.2 times as likely to have a prevalence rate higher than 3 than questions which are not based on a list.

There are other factors that may affect the reporting of disability in a census, including cognition of different questions, use of proxy versus self-reporting<sup>22</sup>, question order, and the context in which the question is asked. Unfortunately there is little research on the impact of these characteristics on the quality of census disability data particularly in developing countries. For this reason, one of the main conclusions of the United Nations Seminar on Measurement of Disability (held in New York from 4-6 June 2001) is the emphasis on the need for further research in these components of question design<sup>23</sup>.

## 6. Revision of the Census Recommendations

Taking into account the development of the ICF and also what we have learned so far about the experience of countries in the application of the current recommendations, the census recommendations could be reviewed in three aspects:

- The approach used to define disability,
- The list of the types of disability, and

---

<sup>21</sup> The findings are related to the probability of having a prevalence rate higher than 3%. The choice of 3% was based on the distribution of the data.

<sup>22</sup> Some results obtained from the 1990 U.S. census and the Content Re-interview Survey reported by Nancy Mathiowetz (2000) shows that proxy respondents tend to report more activity limitations and more severe limitations than self-respondents. However, the impact of proxy or self-reporting is still uncertain in functional limitations linked for example to mental and cognitive impairments.

<sup>23</sup> More information on the meeting can be found at:  
<http://www.un.org/Depts/unsd/disability/methods/index.html>.

- Other aspects related to the design of the question to identify persons with disabilities

## 6.1 Approach used to define disability

The ICF has replaced the ICIDH as the international reference framework for the definition of disability. As with the ICIDH, use of the ICF in the measurement of disability will help change the “culture” of measuring disability from the perspective of the medical model. Use of the ICF concepts in disability measurement may also help change the social perception of disability and its stigmatization.

The ICF is a new classification and as such there is not much experience on the relative performance of questions based on one component or the other in a census situation. There is some country experience on the use of questions based on the activity limitations concept of the ICIDH, but not of the ICF. Furthermore, there is no experience on how the concept of participation can be applied in a census. If at the time of developing the current census recommendations the Handicap domain of the ICIDH was deemed not completely developed for investigation in a census, the ICF now offers the opportunity to investigate the participation of persons with disabilities in different life situations.

## 6.2 List of ICF items to describe types of disabilities

The following list of ICF items is proposed to replace the list in the current recommendations.

1. *Seeing*
2. *Hearing*
3. *Learning and applying knowledge*
4. *Mental functions*
  - a. Attention functions
  - b. Memory functions
  - c. Thought functions
  - d. Higher level cognitive functions
5. *Carrying out daily routine*
  - a. Managing daily routine
  - b. Completing daily routine
6. *Communicating*
  - a. Receiving
  - b. Producing
7. *Changing and maintaining body position*
8. *Carrying, moving, and handling objects*
  - a. Lifting and carrying objects

- b. Fine hand use
- c. Hand and arm use
- 9. *Walking and moving*
  - a. Walking
  - b. Moving around
- 10. *Self care*
  - a. Washing oneself
  - b. Caring for body parts
  - c. Toileting
  - d. Dressing
  - e. Eating
  - f. Drinking
- 11. *Major life activities*
  - a. Education
  - b. Work/employment
- 12. *Community, social and civic life*
  - a. Community life
  - b. Recreation and leisure
  - c. Religion and spirituality

This list should be used with appropriate qualifiers as indicated in the ICF in order to measure the extent or magnitude of the disability.

The ICF offers simpler terms and concepts for disability measurement than did the ICIDH. Like the ICIDH, however, the ICF is a list of so many items that it is not possible to collect data on all its categories. A choice has to be made regarding items considered important for disability policy and programme planning purposes and can also be investigated under census conditions. In a survey, it is possible to collect more detailed information on many more ICF items because there are no space limitations like in a census. The items included on this list are those considered important for assessing the functioning of an individual in their daily living. It is important, however, that the items chosen for inclusion on the census form a subset of items being recommended for investigation in surveys collecting data on disability.

Presently, there is not much national experience to guide the recommendations of items based on the ICF. However, the United Nations (United Nations, forthcoming) still recommends that countries use the activity concept of the ICF as a basis to collecting data on disability although the list of proposed new list of items is a mixture of items on body functions, and activity. This is because of conceptual differences between the ICIDH and ICF. Some of the items – seeing, hearing and behavioural difficulties – in the original disability dimension of the ICIDH are included under body functions in the ICF. Because of the perceived importance of collecting data on these items and also due to the fact that virtually every country collecting data on disability in a census has included them in the question, the United Nations would still recommend them for investigation in a census.

The proposed list is applicable to all the age segments of the population, including children and the elderly. For example, among children, problems with learning are of special importance, while among the elderly, the emphasis tends to be on difficulties with the performance of activities of daily living and also on mental functioning

### 6.3 Design of questions

In many societies, there are socio-cultural pressures to underreport disability. Respondents are reluctant to admit the presence of persons with disabilities in the household and interviewers tend to not ask about disability unless a person with a very severe kind of disability is seen during the interview. Unfortunately, the wording of census questions has not always encouraged a positive or even a neutral reaction of respondents and interviewers.<sup>24</sup> It is important that in countries where disability is stigmatized, instruments to identify persons with disability in a census be designed so that respondents do not perceive that they are being asked about the most stereotyped types of disabilities. It is also important that interviewers receive specialized training on how to conduct the interview.

The following specific issues related to question design should be addressed in the revised census recommendations:

- The questions used should cover as much as possible the definition of the population with disabilities that is used.
- The wording of a question has a great effect on the output of an instrument. Therefore, the language used should be clear, unambiguous and simple. Negative terms should always be avoided. Experience has shown for example that terms such as “long-term”, “disability”, and “handicaps” are viewed as extremely negative and tend to underreport disabilities.
- The choice of response categories should be carefully evaluated to be sure that the respondent is not forced to associate him/her self with a stigma. Scale response items such as *Yes, a lot/Yes, a little/ No* and *Yes, often/Yes, sometimes/No* should be considered for questions used to identify persons with disabilities.
- The context of the question and the mode of data collection are also determinant factors in the overall questionnaire design. In this respect it is a good idea to introduce the question with a few words to help the respondent focus on the new subject.
- Person-based questions should be used instead of household-based questions if

---

<sup>24</sup> Questions such as “Is there anybody in this household who is disabled?” are still used in countries where the stigmatization of the word *disability* is very common.

this does not compromise the overall interview time.

- In designing census questions on disability special efforts should be made to address special population groups such as children, elderly, and persons with psychological and cognitive impairments.<sup>25</sup>

In applying the newly developed ICF framework, consideration should be given to the issue of maintaining comparable time-series data. In countries where data were collected in the past only in relation to the most severe types of disabilities, new questions oriented to broader definitions of disability should also target these most severe types of disability. This would also address the need of users particularly at local level where the key population of interest for service planning is related to the most severe types of impairments (Davis and Gligora, 2001).

The objective of the census recommendations (United Nations, 1998) was to improve the reporting of disabilities by encouraging countries to ask disability status through a checklist of activity limitations. Available information from countries that have already conducted a census in the 2000 round of censuses shows that the checklist approach is not being used. There is a need to find out from the countries why they have not applied the approach recommended by the United Nations recommendations on how to identify the population with disabilities.

At the United Nations Workshop on Disability Statistics for African Countries (United Nations, 2001), the participants recommended, for the region, that the following principles apply in the design of questions to identify persons with disabilities:

- (i) The questions should refer to activity limitations;
- (ii) The questions should ask for activity limitations in the context of a health condition;
- (iii) The questions should ask for type of activity limitation;
- (iv) The questions should allow the respondent to classify his/her degree or severity of activity limitation. Instead of response categories that include only yes/no options, response scale should be designed to include several response options, such as, none/a little/a lot; Yes, sometimes/Yes, often/No);
- (v) The questions should include a time reference to distinguish between long-term and short-term limitations.

---

<sup>25</sup> For example, the experience of the U.K. census shows that it is possible to improve the disability reporting of sub-population groups such as the elderly. A sentence was included at the end of the question: “Include problems which are due to old age” and the disability prevalence rate among elderly reported in the census was higher than the one reported in the survey (British Office for National Statistics, 1998).

## 6.4 User/Producer Dialogue

The importance of the dialogue between producers and users of disability statistics should be strongly emphasized in the census recommendations and practical guidelines should be provided on how to involve stakeholders, including persons with disabilities, in the various activities in the planning process to collect, tabulate and dissemination data on disability. This is because it is important that the data produced by the statisticians be **relevant** to the different stakeholders that plan to use the data for different purposes, including for making policies, developing programmes, advocating for the disability community and for research. In order to ensure this, a partnership between statisticians and the different data users needs to be established. The dialogue should address three questions – “Why”?, “Who”?, and “What?” (United Nations, forthcoming) For the data to meet the needs of the stakeholders, the dialogue should cover, among other things, cover the following:

- a) The policy needs of the data;
- b) What type of information should be collected;
- c) What the “target” population is; and
- d) The coverage of the population of interest.

Disability is a complex phenomenon that involves individual attributes, environment, and time. Producers and users of disability statistics, therefore, need to engage in a constructive dialogue to design instruments that can effectively identify persons with disabilities taking into account what is needed for policy purpose and what is feasible to collect. This is particularly important in situations where resources are scarce and the census is the only source of information for disability.

Although sporadic meetings sometimes take place between statisticians and policy makers to discuss the type of information that should be collected, often the discussions do not cover for example issues related to data collections methods (an issue that is always entirely left to statisticians) and do not include all the stakeholders. While it is important that census statisticians maintain their authority in dealing with methodological issues, it is also important that users understand the impact of the methodology used to collect data on disability and its constraints.

## 6.5 Testing of questions on disability

Countries should be encouraged to pilot test and when possible carry out cognitive testing of the questions. The aim is to measure the validity and reliability of

different types of questions to make sure they measure the concepts they are supposed to measure and that repeated measurements of the same instruments give the same results.

## 7. How to measure the implementation of the recommendations

One of the broad areas of the work of the United Nations Statistics Division towards the improvement of disability statistics is technical cooperation. This is an important avenue for monitoring the implementation of the census recommendations. Technical cooperation is done mainly through training workshops aimed at strengthening national capabilities to produce, disseminate and use data on disability for policy development and implementation. To achieve this, producers and users of disability statistics are brought together to promote understanding of data collection issues and to specify data required for policy formulation. The workshops also provide for the exchange of information and experiences of the participating countries. The WHO *International Classification of Functioning, Disability and Health* are important methodological guidelines for the workshop with regard to the concepts, methods, classifications and instruments to be used to measure disability.

Another way to measure the implementation of the census recommendations is through the continued work of the United Nations Statistics Division on data compilation and dissemination. The Division maintains the United Nations Disability Statistics Database (DISTAT-2), a global database including statistics, indicators and textual information from national data collected on disability issues. DISTAT-2 also provides a comprehensive easily accessible source of information on the methods used in national studies to facilitate the development of better practices in collecting and compiling data on disability. The inclusion in DISTAT-2 of information on methods used to collect data on disability, including on the questions used, is helpful in identify how countries are measuring disability.<sup>26</sup>

There is however, a need to make the compilation and dissemination of data on disability and methodological information part of the regular data compilation and dissemination of the Division. One way this could be done is by requesting data from countries as part of the data collection exercise for the United Nations Demographic Yearbook, which is done on a yearly basis.

## 8. Points for Discussion

1. Is the list presented for the description of types of disabilities adequate? Does it reflect national and international needs? Does it cover the major

---

<sup>26</sup> Available statistics on national sources of data, basic disability prevalence rates, and questions used to identify the population with disabilities are available at: <http://esa.un.org/unsd/disability>.

parts of the ICF? Does it fit in censuses?

2. How should the new recommendations address the conceptualization of disability? Would it be more appropriate to recommend to countries a specific ICF concept (either activity or participation) or to leave the option open?
3. We have limited evidence on how countries can effectively address multiple disabilities in a census. Further investigation is needed to understand why the reviewed countries have not applied the “check list” method suggested in the recommendations. Would it be more appropriate to recommend the use of a generic question followed by the list of disability or to insist on the “check list” approach?
4. There is still not much evidence on the impact of different question characteristics on the quality of data on disability particularly in developing countries. It is clear that impairment questions produce very low prevalence rates and relate only to the most severe types of disabilities. However, activity limitation questions have given mixed results.<sup>27</sup> Further discussions are needed to see how to approach the issue of disability census questions in less developed countries.

---

<sup>27</sup> Using questions based on activity limitations, The Caribbean countries for example obtained prevalence rates that are consistently higher than the ones obtained by the Arab countries using the same types of questions.

## 9. Bibliography

Altman B.M. (2001). Definition of disability and their operationalization. *Research in Social Science and Disability*, Vol. 2, 77-100.

British Office for National Statistics (1998). *Disability and Care: Questions and Needs Considered*, Proceeding of a Conference held on 15 June 1998.

Chamie M. (1989). Survey design strategy for the study of disability, *World Health Statistics Quarterly*, Vol. 42, No. 3, 1989.

Davis E. and Gligora C. (2001). *Comparative analysis of censuses and surveys as instruments to collect data on disability – Australian experience*. Paper presented by Ken Black at the United Nations Seminar on Measurement of Disability, New York 4-6 June 2001.

Durkin M. (2001). *Measurement of Childhood Disabilities in Population Studies*. Paper presented at the United Nations Seminar on Measurement of Disability, New York 4-6 June 2001.

Furrie A.D. (1989). *Comparison of the Results from the 1989 Census and the Health and Activity Limitation Survey for Persons with Disabilities Residing in Households*. Unpublished paper 3 October 1989.

Hess J., Rothgeb J., Moore J., Pascale J., Keeley C. (2001). Measures of Functional Limitations: the effects of person-level vs. household-level questionnaire design. *Research in Social Science and Disability*, Vol. 2, 145-166.

Langlois R. (2001). *The Development of a Global Disability Indicator*. Paper presented at the United Nations Seminar on Measurement of Disability, New York 4-6 June 2001.

Mathiowetz N.A. (2000). Methodological issues in the measurement of work disability. *Survey Measurement of Work Disability, Summary of a workshop*. National Academy Press, Washington 2000.

Mathiowetz N.A. (2001). Methodological issues in the measurement of persons with disabilities. *Research in Social Science and Disability*, Vol. 2, 125-143.

McNeil J. (1993). *Census Bureau Data in Persons with Disabilities: New Results and Old Questions about Validity and Reliability*. Paper presented at the 1993 Annual Meeting of the Society for Disability Studies, Seattle, Washington 1993.

Me A., Mbogoni M. (2001). *Overview over Data Collection Practices in Less Developed Countries*. Presentation made at the United Nations Seminar on Measurement of Disability, New York 4-6 June 2001.

United Nations (1959). *Handbook of Population Census Methods, Volume III Demographic and Social Characteristics of the Population*. Sales No. 58.XVII.6 (Vol.III).

United Nations (1982). *World Programme of Action concerning Disabled Persons* adopted by the United Nations General Assembly at its 37<sup>th</sup> regular session on 3 December 1982, by resolution 37/52.

United Nations (1990). *Disability Statistics Compendium*, United Nations publication, Sales No. E.90, XVII.17.

United Nations (1993). *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* adopted by the United Nations General Assembly at its 48<sup>th</sup> session on 20 December 1993, by resolution 48/96.

United Nations (1998). *Principles and Recommendations for Population and Housing Censuses, Revision 1*. United Nations Publication, Sales No. E.98.XVII.8.

United Nations (2001). *Report of the United Nations Workshop on Disability Statistics for Africa*. United Nations Statistics Division, 2001.

United Nations (forthcoming). *Guidelines and Principles for the Collection of Disability Statistics*

WHO (1980). *International Classification of Impairments, Disabilities and Handicaps*. Geneva, 1980, reprint 1993.

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

## Appendix 1

### Advantages and limitations of using a census to collect data on disability

<b>Advantages</b>	<b>Disadvantages</b>
<p><i>1. To provide small areas data</i></p> <p>The census is the only data collection activity nation-wise that can provide detailed data at the level of the smallest geographic area. Data collected through surveys can hardly be used to estimate disability prevalence even at the smallest level of geographical detail due to the limited sample size and the related sample errors. Data for programme development and analysis at local level can only be collected through a census or a registration system, which is available only in a very limited number of countries.</p>	<p><i>1. Measuring the continuum</i></p> <p>Disability is not a phenomenon that can be easily described with a binary classification yes/no. It is rather an experience that needs to be measured in a continuum to consider several issues such as intensity, duration, and environment. It is important that the instruments used be able to capture as much as possible the different points on this continuum. In this context the design of the question(s) used as a screener to identify the target population with disability should be carefully studied to be sure they do not exclude part of that population. To measure the complexity of this continuum, multiple questions to set context, clarify terminology, and define multiple domains are required. This aspect is particularly difficult in a census where the number of questions asked is restricted.</p>
<p><i>2. To provide data to compare persons with disabilities and persons without disabilities</i></p> <p>Every census collects data on living arrangements, employment, and education and if these characteristics are tabulated for persons with and without disabilities, different levels of participation related for example to education and work and employment<sup>28</sup> can be easily measured.</p>	<p><i>2. Need for extensive training of enumerators</i></p> <p>The main focus of a census is the total counting of the population and their social and demographic characteristics. The collection of data on disability requires extensive training of enumerators on how to ask the questions, which may not be possible in a census.</p>

<sup>28</sup> See chapter 8 of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001)

<b>Advantages</b>	<b>Disadvantages</b>
<p data-bbox="235 254 686 285"><i>3. To allow for time-series analysis</i></p> <p data-bbox="235 306 797 554">It is common in many countries that a census is undertaken on a regular basis, every 5 or 10 years. If data on disability are collected in several censuses, time-series analysis can be performed in relation to disability prevalence rates and participation data.</p>	<p data-bbox="820 254 1203 285"><i>3. Special Population Groups</i></p> <p data-bbox="820 306 1365 590">The use of a short questions in a census tends to underestimate special population groups such as, children, elderly, persons with cognitive and psychological impairments. Specialized surveys where longer instruments can be used are more suitable to measure disability in these sub-population groups.</p>
<p data-bbox="235 600 797 667"><i>4. To use as a sample-frame for a follow-up survey</i></p> <p data-bbox="235 688 797 1045">Several countries, e.g., Canada, France, and New Zealand, have used the census to establish a sample frame for follow-up specialized surveys. In countries where a specialized disability survey is planned, persons identified through the screening module included in the census can provide a frame to more effectively design a sample frame for a more detailed survey on disability.</p>	<p data-bbox="820 600 1019 632"><i>4. Use of proxy</i></p> <p data-bbox="820 653 1344 720">Censuses have an extensive use of proxy respondents.</p>

## Appendix 2

### Census data included in DISTAT-2

Country	Year of the census	Prevalence rate	Country	Year of the census	Prevalence rate
<i>Aruba</i>	1991	<b>5.55</b>	<i>Antilles</i>		
<i>Australia</i>	1976	<b>4.77</b>	<i>Niger</i>	1988	<b>1.31</b>
<i>Bahamas</i>	1990	<b>1.49</b>	<i>Nigeria</i>	1991	<b>0.48</b>
<i>Bahrain</i>	1991	<b>0.81</b>	<i>Oman</i>	1993	<b>1.91</b>
<i>Bahrain</i>	1981	<b>0.99</b>	<i>Pakistan</i>	1981	<b>0.45</b>
<i>Belize</i>	1991	<b>6.57</b>	<i>Panama</i>	1990	<b>1.34</b>
<i>Bermuda</i>	1991	<b>7.56</b>	<i>Panama</i>	1980	<b>0.67</b>
<i>Botswana</i>	1991	<b>2.24</b>	<i>Peru</i>	1993	<b>1.31</b>
<i>Brazil</i>	1991	<b>0.9</b>	<i>Peru</i>	1981	<b>0.18</b>
<i>Bulgaria</i>	1992	<b>1.22</b>	<i>Philippines</i>	1995	<b>1.34</b>
<i>Cape Verde</i>	1990	<b>2.63</b>	<i>Philippines</i>	1990	<b>1.05</b>
<i>Central African Republic</i>	1988	<b>1.54</b>	<i>Poland</i>	1988	<b>9.86</b>
<i>Chile</i>	1992	<b>2.2</b>	<i>Qatar</i>	1986	<b>0.17</b>
<i>Colombia</i>	1993	<b>1.85</b>	<i>Saint Vincent and the Grenadines</i>	1991	<b>7.2</b>
<i>Comoros</i>	1980	<b>1.7</b>	<i>Sao Tome and Principe</i>	1991	<b>3.98</b>
<i>Congo</i>	1974	<b>1.12</b>	<i>Senegal</i>	1988	<b>1.06</b>
<i>Cyprus</i>	1992	<b>3.95</b>	<i>Sri Lanka</i>	1981	<b>0.49</b>
<i>Cyprus</i>	1982	<b>2.26</b>	<i>Swaziland</i>	1986	<b>2.24</b>
<i>Egypt</i>	1976	<b>0.27</b>	<i>Syrian Arab Republic</i>	1981	<b>1.02</b>
<i>El Salvador</i>	1992	<b>1.6</b>	<i>Syrian Arab Republic</i>	1970	<b>1.04</b>
<i>Ethiopia</i>	1984	<b>3.8</b>	<i>Thailand</i>	1990	<b>0.35</b>
<i>India</i>	1981	<b>0.17</b>	<i>Togo</i>	1970	<b>0.55</b>
<i>Iraq</i>	1977	<b>0.93</b>	<i>Tunisia</i>	1994	<b>1.22</b>
<i>Jamaica</i>	1991	<b>4.8</b>	<i>Tunisia</i>	1984	<b>0.87</b>
<i>Jordan</i>	1994	<b>1.23</b>	<i>Turkey</i>	1985	<b>1.37</b>
<i>Kenya</i>	1989	<b>0.75</b>	<i>Uganda</i>	1991	<b>1.16</b>
<i>Kuwait</i>	1980	<b>0.44</b>	<i>United Kingdom</i>	1991	<b>12.15</b>
<i>Liberia</i>	1971	<b>0.8</b>	<i>Viet Nam</i>	1989	<b>5.74</b>
<i>Libyan Arab Jamahiriya</i>	1984	<b>1.46</b>	<i>Yemen</i>	1994	<b>0.54</b>
<i>Libyan Arab Jamahiriya</i>	1973	<b>2.44</b>	<i>Zambia</i>	1990	<b>0.94</b>
<i>Libyan Arab Jamahiriya</i>	1964	<b>3.02</b>	<i>Zambia</i>	1980	<b>1.62</b>
<i>Mali</i>	1987	<b>2.75</b>			
<i>Malta 1995</i>	1995	<b>4.62</b>			
<i>Mauritania</i>	1988	<b>1.5</b>			
<i>Morocco</i>	1982	<b>1.11</b>			
<i>Namibia</i>	1991	<b>3.11</b>			
<i>Netherlands</i>	1981	<b>2.86</b>			

**Appendix 3**  
**Different typologies of questions**

<b>Type 1</b>	<b>Type 2</b>	<b>Type 3</b>
<p><b><u>Bermuda 1991 census, rate: 7.6%</u></b></p> <p>(i) Do you have a physical, mental or other health condition or limitation which has lasted for more than six months and which limits or prevents your participation in the activities of daily life, e.g., work, recreation, mobility, schooling, etc.</p> <p>(ii) Does this condition</p> <p>(a) Limit the kind or amount of work that you can do at a job?</p> <p>(b) Prevent you from working at a job?</p> <p>(c) Limit the kind of amount of activity that you can do at home or at school?</p> <p>(d) Prevent you from going outside the home alone?</p> <p>(e) Prevent you from taking care of your own personal needs, such as bathing, dressing or getting around inside the home?</p> <p>(f) Generally confine you to getting around in a wheelchair?</p>	<p><b><u>Uganda 1991 census, rate: 1.2%</u></b></p> <p>Is anyone who was in the household on census night disabled?</p> <p>Nature of disability: blind; mentally ill; deaf and dumb; polio; amputee; leprosy; cripple; lame; epilepsy; mentally retarded; other.</p>	<p><b><u>Nigeria 1991 census, rate: 0.5%</u></b></p> <p>Nature of disability</p> <p>Not disabled</p> <p>Deaf</p> <p>Dumb</p> <p>Deaf and dumb</p> <p>Blind</p> <p>Crippled</p> <p>Mentally retarded/lunatic</p> <p>Other. Specify.</p>
<p><b><u>Cyprus 1992 census, rate: 4.0%</u></b></p> <p>(a) Are ...'s activities limited because of a long-term physical or mental condition or health problem?</p> <p>(b) Does ... have any long-term disability or handicap</p> <p>(c) What kind of disability or handicap does ... have?</p> <ul style="list-style-type: none"> <li>- Disability of the sense organs</li> <li>- Other physical disability</li> <li>- Psychological disability</li> <li>- Other</li> </ul>	<p><b><u>Philippines 1990 census, rate: 1.1%</u></b></p> <p>(a) Does - have any total and permanent physical or mental disability?</p> <p>(b) What type of disability does - have?</p>	<p><b><u>Oman 1993 census, rate: 1.0%</u></b></p> <p>Type of Handicap</p> <p>Blind</p> <p>One-eye lost</p> <p>One hand or two lost</p> <p>One leg or two lost</p> <p>Deaf</p> <p>Mental disorder</p> <p>Paralysed</p>

<b><u>Bahamas 1990 census, rate: 1.5%</u></b>	<b><u>Aruba 1991 census, rate: 5.5%</u></b>	<b><u>Peru 1993 census, rate: 1.3%</u></b>
<p>(a) Do you suffer from any long-standing illness, disability or infirmity?</p> <p>(b) Does this limit you activities compared with most people your own age?</p> <p>(c) What type of disability or impairment do you have?</p> <ul style="list-style-type: none"> <li>- Sight</li> <li>- Hearing</li> <li>- Speech</li> <li>- Upper limb (arms)</li> <li>- Lower limb (legs)</li> <li>- Neck and spine</li> <li>- Slowness at learning or understanding</li> <li>- Mental retardation</li> <li>- Other</li> </ul> <p>(d) In which of the following are you handicapped?</p> <ul style="list-style-type: none"> <li>- Self-care</li> <li>- Mobility</li> <li>- Communication</li> <li>- Schooling</li> <li>- Employment</li> <li>- None</li> </ul>	<p>(a) Are you (or is he/she) handicapped?</p> <p>(b) What type of handicap is it?</p> <p>Physical Handicap:</p> <ul style="list-style-type: none"> <li>Motor dysfunction</li> <li>Visual handicap</li> <li>Auditory handicap</li> <li>Organ handicap</li> <li>Multiple physical handicap</li> </ul> <p>Mental Handicap:</p> <ul style="list-style-type: none"> <li>Idiocy or imbecility</li> <li>Mental deficiency</li> </ul> <p>Mental and physical handicap</p>	<p>Presenta alguno de los impedimentos siguientes - Has any of the following impairments:</p> <ul style="list-style-type: none"> <li>Ceguera total? - Total blindness?</li> <li>Sordera total? - Deafness?</li> <li>Mudez? - Dumbness?</li> <li>Retardo mental? - Mental retardation?</li> <li>Alteraciones mentales? - Mental alterations?</li> <li>Polio?</li> <li>Pérdide o invalidez extrem. Superior? - Loss or crippled- arm(s)?</li> <li>Pérdide o invalidez extrem. Inferior? - Loss or crippled-leg (s)?</li> <li>Otro? - Other</li> </ul>

## Appendix 4

### Application of the Census Recommendations on Disability in the 2000 Round of Censuses

Country and census year	ICIDH/ICF concept implied by the question used to identify persons with disabilities	ICIDH/ICF categories included in question (the categories reported in bold are those included in the census recommendations)
Bahamas 2000	Activity limitations	<b>Seeing, hearing, speaking, mobility/moving, gripping, learning, behavioural difficulties,</b> mental, other
Belize 2000	Activity limitations	Sight, <b>hearing, speaking, moving/mobility, body movement, gripping/holding, learning, behavioural,</b> other
Canada, 2001	Activity limitations  Participation	<b>Hearing-seeing-communicating-walking-climbing stairs-bending-learning</b> At home, at work or school, in other activities for example transportation or leisure
Costa Rica 2000	Impairment	Severe impairments
Colombia 2003 (draft)	Impairment	Severe impairments
Ecuador 2001	Impairment	Severe impairments
Haiti 2002	Impairment	Severe impairments
India 2001	Impairment	<b>Seeing,</b> speech, <b>hearing,</b> movement, mental
Jamaica 2001	Impairment	Sight, hearing, speech, physical disability, multiple disability, slowness of learning, mental retardation, mental illness, other
Mauritius 2000	Activity limitation	<b>Speaking, hearing, seeing, mobility, walking, manual activities (fingering, gripping, holding), learning, behaviour, personal care</b>
Namibia 2001 (draft)	Impairment	Severe impairments
New Zealand 2001	Activity limitation  Impairment	Communicating or socializing
Palestine 1997	Impairment	<b>Speaking, hearing,</b> hearing and speaking, <b>seeing, moving,</b> grasping, mental, mental and moving, multiple
Saint Lucia 2001	Impairment	Sight, <b>hearing,</b> speech, upper limb, lower limb, neck and spine, slowness at learning, behavioural/mental retardation, other
South Africa 2001	Participation	Sight, <b>hearing,</b> communication, physical, <b>intellectual, emotional</b>
Tanzania 2002 (draft)	Impairment	Severe impairments
Trinidad and Tobago	Activity limitations	<b>Seeing, hearing, speaking,</b>



## Appendix 5

### The DISTAB Project

The initial DISTAB group was composed of members from five countries (U.S., Canada, the Netherlands, France and South Africa) and the United Nations Statistics Division. The members of the DISTAB group by country or organization are as follows: U.S. (Paul Placek, Gerry Hendershot, Kristine Mulhorn, Don Lollar, Diane Shinberg, Gretchen Swanson, and LeeAnne Carrothers), Canada (Renée Langlois), France (Catherine Barral and Dominique Velche), the Netherlands (Marijke de Kleijn de Vrankrijker and Rom Perenboom), South Africa (Margie Schneider, now of WHO) and the United Nations Statistics Division (Margaret Mbogoni). The project is sponsored by NCHS and began in 1999. Members of the DISTAB group meet monthly by conference call and annually in person.

Canada is using the 1991 Health and Activity Limitation Survey; France is using the 1999 Enquete handicaps, incapacites dependance questionnaire a l'aidant principal; Netherlands is using the 1997-98 Netherlands Health Interview Survey; South Africa is using the 1998 Questionnaire for People with Disabilities, and the U.S. is using the 1994-95 National Health Interview Survey on Disability.

Although the DISTAB group was initially formed to evaluate the usability of the Draft Beta-2 version of the ICF in surveys, its aims have evolved over time to include also a quest for the improvement of international comparability of disability measurement. DISTAB based its initial work on the tabulations on disability characteristics included in the United Nations Principles and Recommendations for Population and Housing Censuses, Rev. 1. Initial work of the DISTAB project involved back coding of disability categories for the five surveys based on the recommended tabulations on disability in the United Nations census recommendations. The disability items identified from the questions used were back coded using the terminology and coding categories of the ICIDH-2, Beta 2. Prior to being evaluated for comparability and reliability the items were re-coded to ICF.

A comparison of the back coded items showed a large variability in the instruments used and highlighted the need for harmonization of methods used in the measurement of disability. Out the analysis, a paper has been written and sent for publication. The title of the paper is - *Comparing Disability Survey Questions in Five Countries: A Study Using ICF to Guide Comparisons*. The Group also intends to publish the statistical estimates that resulted from the back coding exercise.

In view of the observed differences between the studies in the questions used, DISTAB recommended that the United Nations convene an international meeting to address the issue of disability measurement with a focus on the design of questions. In response to this recommendation, the United Nations Statistics Division organized and hosted the United Nations International Seminar on the Measurement of Disability, which took place in New York in June 2001. At the end of the international seminar, seven

priority areas were identified for further work to improve the measurement of disability. It was agreed that a city group be established to implement the recommendations of the seminar and the US National Center for Health Statistics (NCHS) agreed to host the first meeting that is now taking place.

Following the international seminar, the DISTAB developed a new and expanded agenda, and Australia and Japan also expressed an interest to join the project. Currently, the representatives of the five surveys are working on two of the newer agenda items:

1. An inventory of questions used in the respective surveys to measure Participation and Environment.
  
2. Comparative study of the quality profiles for the respective surveys. The objective is to provide a broad view of how the surveys compare in terms of aims, methodology and definitions used, and describe the context of the survey. The quality profiles include items on:
  - a. Overview of the study
  - b. Sampling
  - c. Evaluation of coverage based on external data
  - d. Response and non-response
  - e. Measurement error
  - f. Data evaluation
  - g. Estimation and sampling error
  - h. Survey content
  - i. Type of respondent
  - j. Data processing, imputation and quality control
  - k. Special procedures for persons with disabilities

The group is working towards having a published paper on the methods used for each study, including the information on the survey quality profiles.