

General disability measures in developing countries – relationship to purposes for measurement

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A. Introduction

1. In many developing countries, the population census is the only source of data on disability. The questions used, however, are very often limited in scope and refer mainly to a list of a few severe impairments, such as those who are blind, deaf, mute, paralysed, and mentally retarded. In fact, information available in the United Nations Disability Statistics Database, DISTAT ¹, shows that most developing countries included in the database used a checklist of impairment to identify the population with disabilities.
2. The present report reviews the characteristics of general disability measures used in the 2000 round of censuses of selected developing countries. The characteristics of the general measure are those developed at the first meeting of the Washington Group on Disability Statistics in 2002 and further developed by the working group on the matrix linking the purposes of general measures of disability to purposes for measurement (the United Nations Statistics Division, National Center for Health Statistics of the US, and the National Institute of Statistics of Italy). The characteristics of the general measure(s) used in the selected countries are also mapped on to a theoretical matrix developed by the working group that cross-classifies the characteristics of the general measures to the purposes for which data are needed.
3. Ten countries are included in the review: Bahamas, Belize, Brazil, Egypt, Jamaica, Mauritius, South Africa, Saint Lucia, Trinidad and Tobago, and Turks and Caicos.
4. The choice of country studies for the review of the characteristics of questions on disability was made to give a broader view of different types of questions used in censuses during the 2000 census round. For a closer look at the questions used in the ten countries see Annex 1.

B. Characteristics of questions used to identify persons with disabilities

5. Table 1 (below) presents the characteristics of the questions for the ten reviewed countries. The characteristics being considered include:
 - 1) the ICF domain covered by the question(s)
 - 2) whether or not duration of disability is specified in the question
 - 3) type of response categories – dichotomous or multiple response categories
 - 4) whether in the question the condition/limitation is attributed to a health condition
 - 5) whether or not the question uses negative or neutral terminology
 - 6) whether or not question makes reference to a norm
 - 7) whether or not the question is simple or complex
 - 8) whether or not the question is age oriented
 - 9) whether there is reference to mental functioning in screening question or in types of conditions

¹ DISTAT is a global database including statistics, indicators and textual information from national data collected on disability issues, and was first published in 1988.

- 10) total number of questions used to identify persons with disabilities
- 11) total number of questions asked on disability

6. In terms of the ICF concepts, all the countries, except Egypt, asked questions that covered both activities and participation and also body functions and structures. This said, however, it should be noted that there are differences between the countries in the content of questions with regard to the ICF concepts used as can be seen from annex 1. For example, in Bahamas, only four of the nine categories of disability are on body functions and body structures, whereas in South Africa on the other hand, only one of the seven items is on activities and participation, and the rest are body functions.

7. With regard to duration, none of the ten countries asked a question that has a specified time reference. In five of the countries, however, the questions included a variety of term that refer to duration, such as, the presence of a long-standing illness/disability/infirmity (Bahamas, Saint Lucia, and Trinidad and Tobago); to a long-term physical/mental condition or health problem (Mauritius) or to a long-lasting condition (Turks and Caicos).

8. All the countries used dichotomous response categories of either “Yes” or “No”, except Brazil that used multiple categories or degrees of difficulty in functioning – “Unable”, “Great permanent difficulties”, “Some permanent difficulties” and “No difficulties”. In addition, only Jamaica and Mauritius make reference to a standard or norm in the questions asked – “compared with most people of the same age” and “in a manner considered normal for a person of his/her age”, respectively. Only Mauritius asked a question that makes reference to a norm and is also age oriented (..any limitation to perform a daily-life activity in a manner considered normal for a person of his/her age).

9. Furthermore, while some countries used one question to collect information on persons with disabilities (Belize, Egypt, Mauritius and South Africa), others used more than one question. For instance, in the Bahamas, Jamaica, Saint Lucia, and Trinidad and Tobago, a general question is asked about the participant having a long-standing illness or disability, or whether he/she suffers from a disability or infirmity. This is followed by another question about areas in which the respondent has difficulties or has impairments.

10. Attribution of disability to a health condition is reflected in the questions used in three of the countries - the Bahamas, Mauritius and Turks and Caicos - where the questions included phrases such as “does the disability or illness affect you in any of the following?”; “because of a long-term physical/mental condition or health problem”; “affected by any long-lasting condition”; “been diagnosed as suffering from”.

11. For the majority of the countries the questions used contain negative terminology. This includes use in the questions of terms such as “disability”, “problems”, “dumb”, “suffer(ing)”, “infirmity”. Also, while most of the questions may look simple they could be characterized as complex since they use terms that may be interpreted differently by

respondents, such as the phrase “long-standing illness or disability”, or even a question that asks if the respondent suffers from any disability or infirmity.

12. All the countries, except Brazil, included an item on mental functioning in the types of conditions (behavioural difficulties, learning difficulties, mental retardation, etc.). Only Brazil and Mauritius, however, use screening questions that make reference to mental functioning – “do you have any permanent mental disabilities that limit you in your daily activities?” and “..because of a long-term physical/mental condition..?”

13. The experience of Brazil and Turks and Caicos is different from the other countries in that they asked separate questions covering the different components of the ICF. In Brazil, five questions were asked to identify the population with disabilities about activity limitations/participation restrictions due to mental difficulties, seeing difficulties, hearing difficulties, difficulty walking/climbing stairs, and a question on the presence of a list of severe impairments. In Turks and Caicos, there was a question on impairments followed by two questions on activities and participation.

14. In terms of the characteristics of the questions included in the table, none of the questions covered the environment (including use of assistive devices), and duration of the condition or severity. On the other hand, all the questions that ask about activities and participation refer to performance rather than capacity.

Table 1: The characteristics of questions used to measure disability in selected countries

Characteristics of Questions													Reference to mental functioning?			
Countries	General Measure	Type of conditions	Availability of Results	Percentage of persons with disabilities	ICF Domain	Duration specified? (long term/short term disability)	Dichotomous /Multiple response categories	Attribution to a health condition	Use of neutral terminology in question	Reference to a norm	Simple/Complex	Age-oriented	In screening	In types of conditions	# of questions to identify persons with disabilities	# of questions on disability
Bahamas, Census 2000	Yes	A, P	No	N/A	BF, BS	Long term	D	Yes	No	No	Complex	No	No	Cognitive and Psychological	1	5
Belize, Census 2000	Yes	A, P	No	N/A	BF, A, (P)	No	D	No	Yes	No	Complex	No	Cognitive	Cognitive	7	7
Brazil, Census 2000	Yes	BF, BS, A, P	No	14% ¹	BF, BS, A, P	No	D/M	No	Yes	No	Complex	No	Cognitive and Psychological	Cognitive and Psychological	5	5
Egypt, Census 1996	Yes	Open	Yes	0.48% ²	BF, BS	No	D	No	No	No	Complex	No	No		1	1
Jamaica, Census 2001	Yes	BF, BS, A	No	N/A	BF, BS	No	D	No	No	No	Complex	No	No	Cognitive and Psychological	1	3
Mauritius, Census 2000	Yes	A, P	No	3.46% ³	A, P	Long term	D	Yes	No	Yes	Complex	Yes	Cognitive and Psychological	Cognitive and Psychological	1	2
Saint Lucia, Census 2001	Yes	BF, BS, A	No	5.1% ⁴	BF, BS	Long term	D	No	No	No	Complex	No	No	Cognitive and Psychological	1	2
South Africa, Census 2001	Yes	BF, BS, A, P	No	N/A	P	No	D	No	No	No	Complex	No	No	Cognitive and Psychological	1	2
Trinidad and Tobago, Census 2000	Yes	BF, A	No	N/A	A	Long term	D	No	No	No	Complex	No	No	Cognitive and Psychological	1	2
Turks and Caicos, Census 2001	No		No	N/A	BS, BF, A, P	Long term		Yes	No	No	Complex	No	No	Yes	3	3

BF – Body functions, BS – body structures, A – Activity, P – Participation, D - Dichotomous, M – Multiple categories

1) – Personal telephone communication with Ms. Alicia Bercovich, Coordinator of the 2000 census of Brazil (27 January 2003).

2) Disability Statistics in Egypt by Dr. Bothania EL-Deeb. Paper presented at Washington Group meeting Jan 2002 in Ottawa, Canada

3) Republic of Mauritius, Ministry of Economic Development, Financial Services and Corporate Affairs 2000 Housing Populations Census Volume VII: Disability

4) Questions on Disability raised in the last Census in St. Lucia, by Ethel Jn. Baptiste. Paper presented at Washington Group meeting Jan 2002 in Ottawa, Canada

C. Linking characteristics of questions to purposes for measurement

15. Ideally, the data that is collected as well as the scope and content of questions used to elicit the information should be based on national data needs, which are determined through consultations with data users. It is expected that national data needs and priorities will differ between countries depending on national concerns with regard to disability issues. In the area of disability, the World Programme of Action concerning Disabled Persons², has however, identified three major goals for policy formulation and programme planning - Equalization of opportunities³, Prevention⁴, and Rehabilitation⁵. These major goals provide a valuable guide for determining the purpose for which data on disability are needed.

16. Table 2 below presents a matrix on the purposes of measurement and the characteristics of existing questions on disability from selected countries. The questions used, in terms of their characteristics, are mapped on to the purposes for which the data could be used. The information in the matrix shows that for each of the selected countries, the question(s) can be used for all the three policy and programme areas of equalization of opportunities, prevention and rehabilitation.

17. In all the countries, the questions asked can be used to assess equalization of opportunities as they set the scope of the population at risk for reduced participation. It should be noted, however, that the identified population at risk would differ between the countries because of differences in questions used. For example, it is expected that the population identified as being at risk for reduced participation would be higher in the Bahamas, Belize, Mauritius, Trinidad and Tobago and Turks and Caicos due to use of activity limitation based questions compared to Egypt where the question is based on a list of severe impairments. We should bear in mind, however, that while these questions will provide information on the population at risk they are aimed for the most part on performance of simple daily activities, such as walking and moving. They do not focus on the performance of major life roles based on the ICF that can be used to assess the participation of persons with disabilities in society. These areas include participation in work, education, playing, and social life. In population censuses, however, it is common practice to ask information on education and economic characteristics of the population. This information, when cross-classified by disability status would give an indication of

² *World Programme of Action concerning Disabled Persons*, United Nations, New York, 1983.

³ Equalization of opportunities - The process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities are made accessible to all.

⁴ Prevention - Measures aimed at preventing the onset of mental, physical and sensory impairments (primary prevention) or at preventing impairment when it has occurred, from having negative physical, psychological and social consequences.

⁵ Rehabilitation - A goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimal mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment.

the extent to which persons with disabilities participate in these life roles compared to those without disabilities.

18. The questions used in almost all the selected countries, except for Egypt, are useful for providing information necessary for the design and provision of rehabilitation services. Information on difficulties in the performance of activities and participation is useful for planning ways to improve the performance of the individuals concerned in a particular area.

19. Prevention can be either primary or secondary in nature. With regard to primary prevention, information is needed on disabling conditions as an important input into programme development. In this case, information on impairments related to body functions and body structures is useful for development measures to prevent the onset of the conditions. Sometimes, the interest is in the prevention of further loss of function for a person who already has either an impairment, activity limitation or participation restriction (secondary prevention). Examples of secondary prevention would include provision of rehabilitation services in the form of medications to a person with mental impairments to help their functioning in society and prevent them from being socially isolated. Secondary prevention could also include providing environmental accommodations in the form of ramps to prevent lack of access to buildings for persons with mobility problems in order to enhance their participation in society. Depending on what the data are needed for, information on impairments, such as that collected in Egypt or on activities and participation as that collected in the other countries would be useful for the development of prevention programmes.

Table 2: Matrix on the purposes of measurement and characteristics of general disability questions

Examples from the 2000 census round in ten countries

Purpose of Measurement	Characteristics of Questions				
	Environment	Assistive Device	Participation	Activity	Body Functions/ Body structures
Equalization of Opportunity			Ba Be J M SA T TC	Ba Be J M SA T TC	Ba Be Br E J M SL SA T TC
Rehabilitation Needs			Ba Be Br M SA T TC	Ba Be Br M SA T TC	E
Prevention					Ba Br E J SL SA TC

Ba-Bahamas, Be-Belize, Br-Brazil, E-Egypt, J-Jamaica, M-Mauritius, SA-South Africa, T-Trinidad and Tobago, TC-Turks and Caicos

D. Conclusion

20. There have been changes in the last decade in the type of questions used to measure disability in many developing countries, from impairment based to activity limitation/participation restriction type of questions. The review of questions used to measure disability in the selected developing countries, however, shows that there are still major differences between the countries with regard to the characteristics of the measures used.

21. In order to produce statistics that are comparable between countries, there is a need, therefore, to further refine instruments used to measure disability. Furthermore, the development of the ICF as a framework for the assessment of human functioning calls for the development of appropriate questions based on this international guide. Use of the ICF framework and terminology would improve the international comparability of the question used and also of the statistics produced.

22. With regard to purposes for measurement of disability, national needs for data differ. When questions are designed, however, it is important to ensure that they have the characteristics that will ensure that the data collected meet the needs they are expected to fulfill. At the international level, the development of a general measure of disability that will meet diverse data needs on disability may not be an easy task. As a starting point, however, there is a need to narrow down the proposed list of purposes from that currently proposed by the working group on the matrix to that included in the World Programme of Action concerning Disabled Persons. By doing so we will have comparable broad purposes between countries. Without a manageable list of purposes, it will be a daunting task to develop a measure, for international use, that will fit a long list of purposes.

Annex 1: Census questions used to identify people with disabilities in selected countries

Bahamas 2000

Commonwealth of the Bahamas “Census of Population and Housing 2000” Enumerator’s Manual

1. Do you have any long-standing illness or disability?
2. Does this disability or illness affect you in any of the following?
 - a. Seeing (even with glasses, if worn)
 - b. Hearing (even with hearing aid, if worn)
 - c. Speaking (talking)
 - d. Mobility/moving (due to absent or impaired limb)
 - e. Mobility/moving (due to localized, paraplegic, quadriplegic paralysis)
 - f. Gripping (using fingers to grip or handle objects)
 - g. Learning (intellectual difficulties, slowness)
 - h. Behavioural difficulties (psychological, emotional problems)
 - i. Mental (mild, moderate, severe retardation)
 - j. Other

Belize 2000

“Population & Housing Census. Census Day – May 12, 2000” Questionnaire

1. 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
 - g. Learning difficulties (intellectual difficulties, retardation)

Brazil

Instituto Brasileiro de Geografia e Estatística “Censo Demográfico 2000” Questionnaire

1. Do you have any permanent mental disabilities that limit you in your daily activities? (As working, going to school, playing, etc.) Yes/No
2. How do you evaluate your capacity to see? (Even with glasses or contact lenses, if used)
 - a. Unable
 - b. Great permanent difficulties
 - c. Some permanent difficulties

d. No difficulties

3. How do you evaluate your capacity to hear? (Even with hearing aid, if used)

a. Unable

b. Great permanent difficulties

c. Some permanent difficulties

d. No difficulties

4. How do you evaluate your capacity to walk/climbing stairs? (Even with walking aids, if used)

a. Unable

b. Great permanent difficulties

c. Some permanent difficulties

d. No difficulties

5. Do you have any of the following disabilities?

a. Total permanent paralysis

b. Permanent paralysis of legs

c. Permanent paralysis of one side of the body

d. Loss of a member: leg, arm, hand, foot or thumb

e. None of the preceding options

Egypt 1996

“Disability Statistics in Egypt” Dr. Bothaina EL-Deeb. Paper for the Washington Group, 2003

1. Blind

2. Loss of one eye

3. Deaf and dumb

4. Deaf

5. Dumb

6. Loss of one or both arms

7. Loss of one or both legs

8. Mental retardation

9. Poliomyelitis

10. Paralysis (total or partial)

11. Other disabilities

Jamaica 2001

Jamaica “Population and Housing Census 2001” Questionnaire

1. Do you/does ... suffer from any disability or infirmity?

2. Does the disability limit your/his/her activities compared with most people of the same age?
3. What type of disability do you/does ... have?
 - a. Sight only
 - b. Hearing only
 - c. Speech only
 - d. Physical disability only
 - e. Multiple disability
 - f. Slowness of learning
 - g. Mental retardation
 - h. Mental illness
 - i. Other

Mauritius

**Republic of Mauritius Ministry of Economic Development, Financial Services and Corporate Affairs
Central Statistics Office "2000 Housing and Population Census. Volume VIII: Disability"**

1. Does the person experience any disability (i.e., any limitation to perform a daily-life activity in a manner considered normal for a person of his/her age), because of a long-term physical/mental condition or health problem? Yes/No.
 - a. Speaking and talking disabilities
 - b. Hearing and listening disabilities even with hearing aid
 - c. Seeing disabilities even with glasses
 - d. Walking, running and other ambulation disabilities
 - e. Manual activity disabilities such as fingering, gripping and holding
 - f. Disturbance of ability to learn and acquire education
 - g. Disturbances of behaviour, including antisocial behaviour, maladjustment and liability to self injury
 - h. Inability to look after oneself with regard to personal care and hygiene, feeding, etc.
 - i. Other disabilities

Saint Lucia

Organisation of Eastern Caribbean States, "2001 Population and Housing Census" Questionnaire

1. Does --- suffer from any long-standing illness, disability or infirmity? Yes/No
2. What type of disability or impairment does --- have?
 - a. Sight (even with glasses if worn)
 - b. Hearing (even with hearing aid if used)
 - c. Speech (talking)
 - d. Upper limb (arm)
 - e. Lower limb (legs)

- f. Neck and spine
- g. Slowness at learning or understanding
- h. Behavioural (mental retardation)
- i. Other, please specify

South Africa

Statistics South Africa “Census 2001 Household” Questionnaire

1. Does (the person) have any serious disability that prevents his/her full participation in life activities (such as education, work, social life)? Yes/No.

- a) None
- b) Sight (blind/severe visual limitation)
- c) Hearing (deaf, profound hard of hearing)
- d) Communication (speech impairment)
- e) Physical (e.g., needs wheelchair, crutches or prosthesis; limb, hand usage limitations)
- f) Intellectual (serious difficulties in learning)
- g) Emotional (behavioural, psychological)

Trinidad and Tobago 2000

Republic of Trinidad and Tobago, Central Statistical Office “Population and Housing Census May 15, 2000” Questionnaire

1. Does --- suffer from any longstanding disability that prevents him/her from performing an activity? Yes/No.

2. Does --- have any difficulties in?

- a. Seeing (even with glasses if worn)
- b. Hearing (even with hearing aid if used)
- c. Speaking (talking)
- d. Moving/mobility (walking, standing, climbing stairs)
- e. Body movement (reaching, crouching, kneeling)
- f. Gripping
- g. Learning
- h. Behavioural
- i. Other

Turks and Caicos 2001

Turks and Caicos Islands, Department of Economic Planning and Statistics “Commonwealth Caribbean Population and Housing Census, August 2000” Questionnaire

1. Has ... been diagnosed as suffering from any of the following long lasting conditions or diseases?

- a. Blindness/severe visual impairments

- b. Deafness/severe hearing impairments
- c. Dumbness/speech impediment
- d. Paralysis/limb impairment/loss of limb
- e. Mental retardation
- f. Other

2. Which of the following basic activities are affected by any long lasting condition that you may have?

- a. Walking, standing, climbing stairs
- b. Reaching, lifting, kneeling, carrying
- c. Gripping
- d. Seeing
- e. Hearing
- f. Speaking/talking
- g. Learning, remembering, concentrating
- h. Behavioural
- i. None

3. Does ... disability or condition affect ... from performing any of the following activities?

- a. Taking care of yourself
- b. Getting around within the home
- c. Going outside the home
- d. Working at a job or business
- e. Undertaking educational activities
- f. Communicating
- g. None