Assessment of the disability indicator available through IPUM-International for the calculation of healthy life expectancy

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Abstract

In view of global and active ageing, the healthy life expectancy which measures the status of health of population is attracting attention in many countries. However, defining health is a difficult task and various measures are being used for the calculation of healthy life expectancy.

The disability indicator harmonized through Washington Group, composed of 119 countries' national statistical authorities and relevant international organizations, is started to be used in censuses and as of October 2014, among the 33 countries with available round 2010 census data on IPUMS-International, 29 countries' data contain information on disability. For the moment, not all of these countries adopt the disability question in identical manner but the comparison of data proved that the disability rates are comparable if certain conditions are met.

There are number of countries where the disability data are not available through census. The notable example is Japan which offers data on disability through sample surveys and registration data. These data will be compared with census data of other countries and the possible implications will be drawn.

Keywords: Disability, Census, Washington Group, IPUMS-International

I. Background

"Disability" used to be the term to designate the condition of impairment such as blind, deaf, dumb or crippled. Recent progress of society and scientific knowledge let the international community to alter the perception. Now the disability is defined as "long-term physical, mental, intellectual or sensory impairment" according to the Convention on the Rights of Persons with Disabilities and ICF, International Classification of Functioning, Disability and Health defines disability, together with functioning, as "umbrella terms denoting the positive and negative aspects of functioning from a biological, individual and social perspective". It is a person centered approach to assess the physical or psychological functioning rather than the identification of diseases or problems, and anyone might suffer from disability in life.

The national census is the most comprehensive way to obtain the disability statistics, covering all nationals regardless of the age or type of residence, and the disability status is one of the

25 core topics stipulated in the UN Principles and Recommendations for Population and Housing Censuses (2008) in which it is recommended to include the 4 essential domains of disability namely Walking, Seeing, Hearing, Cognition and 2 less prioritized domains of Self-care and Communication.

The Washington Group, one of the city groups of UN Statistical Commission, was formed in 2001 in order to facilitate the comparison of data on disability cross-nationally. It made a proposition to standardize the disability question of census as following 6 questions with 4 response categories;

< Questions >

Because of a health problem :

1) Do you have difficulty seeing even if wearing glasses?

2) Do you have difficulty hearing even if using a hearing aid?

3) Do you have difficulty walking or climbing stairs?

4) Do you have difficulty remembering or concentrating?

5) Do you have difficulty with (self-care such as) washing all over or dressing?

6) Using your usual (customary) language, do you have difficulty communicating (for example understanding or being understood by others)?

< Response categories >

No - no difficulty; Yes - some difficulty; Yes - a lot of difficulty; Cannot do at all

The judgement of being disabled or not is defined as those who have at least one domain that is coded as a lot of difficulty or cannot do it at all (Madans 2014).

Using these frameworks of census disability question, this paper examines the actual state of application in national censuses. For the census round of 2010, 52 countries included disability questions as of 2010 (Osaki-Tomita 2010). By using the IPUMS-International, 29 countries' datasets containing the information of disability of the 2010 round census were identified as listed in the Annex Table 1 and used for analysis.

II.   Description of the disability data

Among 29 countries, the types of questions are varied and for now, no country use yet the short set of questions as proposed by the Washington Group in the identical manner. The types of disability also vary but can be summarized as in Table 1.

Table 1 Type of disability asked in 29 countries in 2010 round censuses

Category (N)	**Other words employed** (author's English translation in case of other language)
Seeing (28)	vision; blind; visual handicap; severe visual limitation
Hearing (28)	deaf; auditory handicap; profoundly hard of hearing
Speaking (18)	mute; voice disorder; communication; speech impairment
Intellectual / Mental (26)	autistic; mental deficiency; cannot learn, understand, remember, paying attention to, making decisions or concentrate; emotional, behavioral or psychological disorder; mental handicap; mental limitation; mentally retarded
Physical (28)	difficulty in walking or climbing stairs, in movement, in using hand(s); needs wheelchair, crutches; loss of hand(s)/arm(s)/leg(s); hand(s)/leg(s)/torso amputation/ impairment; limited use of leg(s)/arm(s), handicap of upper/lower limb; pain, breathing or other chronic illness or condition
Self-care (8)	dressing, bathing, eating by oneself or getting around inside the home, grasp objects and / or open containers with hands
Participation (3)	doing errands alone; going outside alone, working; other activities for example leisure or using transport

* Number in Category denotes the number of countries which asked the category of question. For the country list, refer Annex Table 1,

Seeing, Hearing and Physical categories are included in almost all countries. The exception is Liberia where the type of disability was asked without choices, so the coded data are not available. Intellectual/Mental category was not asked in Liberia, Malawi and Peru and might be included in the "other" category. By nature, Intellectual and Mental should be separated but in many cases, they are used in mixed manner.

To assess physical disability, in addition to the conventional notion of disability such as arm or leg amputation, number of countries use "difficulty in walking or climbing stairs" as in the Washington Group short set of questions. Self-care question is adapted by 8 countries and participation question is adapted by 3 countries, much less than the Seeing, Hearing, Intellectual/Mental and Physical. The category of Speaking is used less compared to Hearing. However, in Panama and South Africa, Speaking is termed in conjunction with Communication which would suggest that the less usage of Speaking would be compensated by adding the Communication question in the future.

In addition to the questions on the type of disability, some countries ask the cause, duration of disability or if the person is attending the special school. Specific disease or symptom is included in case of Egypt (polio) or Zambia (Albino). Alternative disability information is often

available from employment section of the census, when the disability is included in one of the causes of unemployment, which is the case of 17 countries among 29. However, the disability as a cause of unemployment excludes the retired age disability so it is not taken into the analysis in this study.

Most countries adapt the Yes or No binary response categories or ask the respondent to check the applicable category. Indonesia provides 3 response categories No/Some/Total (difficulties) and 3 countries, Brazil, Uruguay and Vietnam, provide 4 response categories as stipulated in the Washington Group short set of questions.

III.   Comparison of age-specific disability rate

It would be convenient to define single indicator of disability to compare between countries. Here, the definition similar to that of Washington Group was employed; counting people as disabled who responded Yes or check at least one type of disability category in case of countries with 2 response categories. For countries with 3 or 4 response categories, those who responded as the severer two responses, Total or Some in the case of Indonesia and "A lot of difficulty" and "Cannot do it at all" in the cases of 4 response categories countries are considered to be disabled. As 3 countries ask the disability not on personal basis but household level, the remaining 26 country-data are used. In most of the countries, the IPUMS harmonized variable of "Disable" was used except Brazil, Indonesia, Panama, Puerto Rico, USA, Uruguay, Vietnam due to the difference of cut-off definition or inconsistency of the variable. Figure 1 shows the age-specific disability rate of 26 countries.
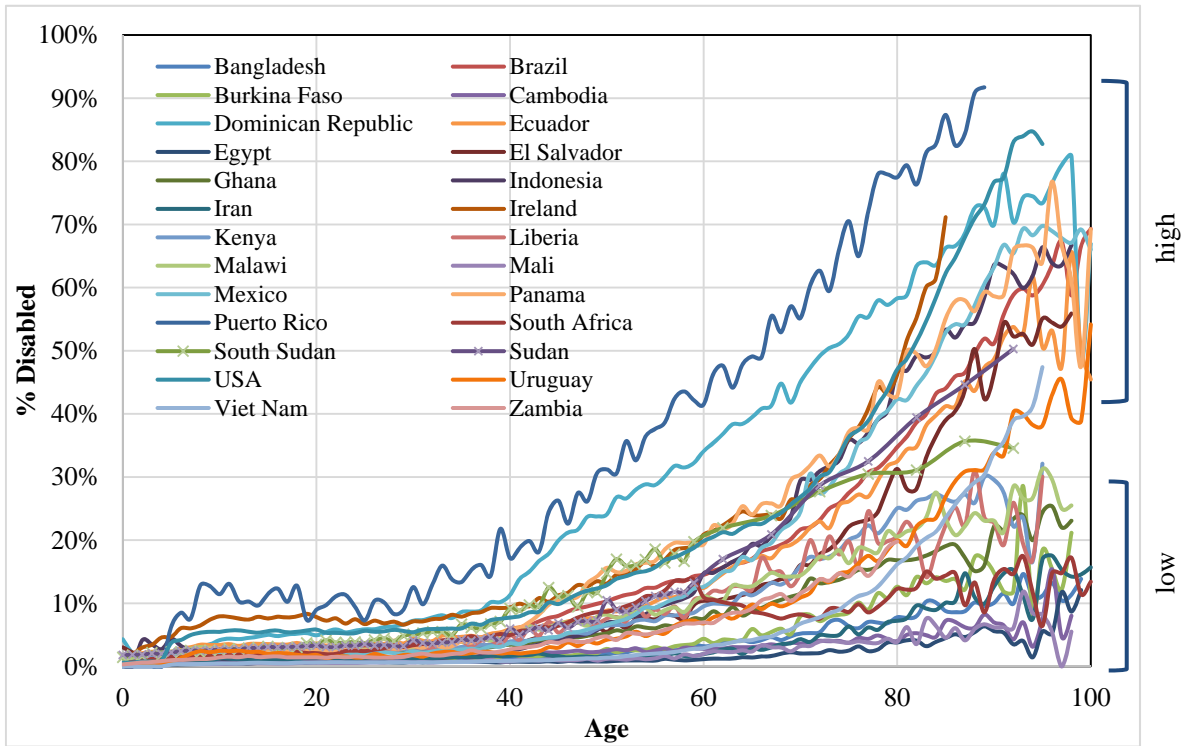
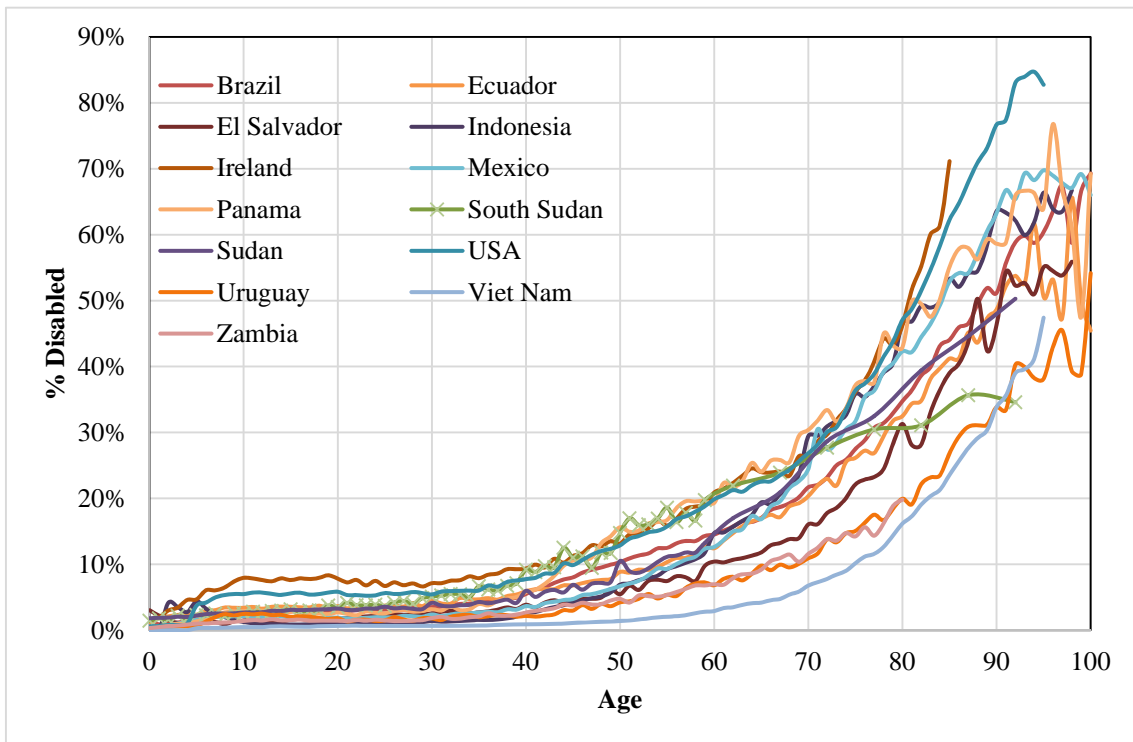**Figure 1 Age-specific disability rate of 26 countries**

Figure 2   Age-specific disability rate of selected 13 countries

note : Sudan and South Sudan data are smoothed by every 5 years after 60 years old due the strong age heaping.
Source : Census microdata through IPUMS. The year of the census is listed in Annex Table 1.

There is quite a variation in the age-specific disability curve. However, one can notice that there is a group of countries that the curve does not go up as high in the old ages compared to the other group which shows high increase in the old ages. The "low" countries include Bangladesh, Burkina Faso, Cambodia, Egypt, Ghana, Iran, Kenya, Liberia, Malawi, Mali and South Africa, all of which are asking disability question by either using a filter question such as "are you disabled? If so then…" or clearly insert the word Disability or Handicap in the question text. It has been observed that the word "disability" evokes certain negative stereotype and it can be anticipated that the people might answer "No" to the census question even if she/he has difficulties in reality, thus creating the distortion of the data. It is ironical that the disability question should not use the word "disability", but the data show the reason clearly.

The rest of the countries in the "high" group adapt the question using the phrase of "having difficulties in…" instead of "are you disabled". Except for Puerto Rico and Dominican Republic, the age-specific rates vary but can be considered that they are within a reasonable range (Figure 2). The disability rates of all age are shown in Annex Table 1.

When the 13 countries of Figure 2 are observed, it is found that the higher the proportion of elderly, the higher the disability rate is. There is a strong correlation (r = 0.616) between the disability rate and proportion aged 65+ (Figure 3).
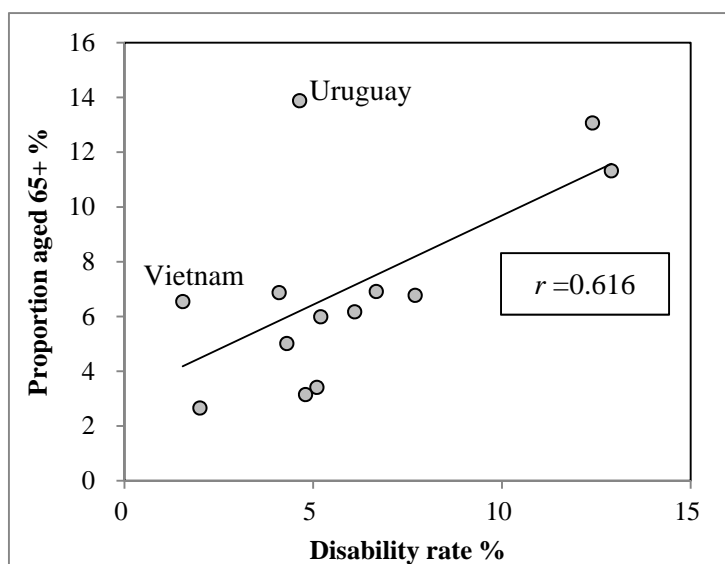

Figure 3   Disability rate and proportion aged 65+

Source : The disability rate is calculated by author from census microdata through IPUMS. Proportion aged 65+ is the figure of 2010 by UN World Population Prospects: The 2012 Revision

Among the 13 selected countries, the lowest rate is found in Vietnam. As mentioned earlier, there are 3 countries, Brazil, Uruguay and Vietnam which use 4 response categories conforming to

the Washington Group proposition. For these countries, the cut-off point to determine the disability rate is the severer 2 categories ("Cannot do it at all" and "Great difficulty"). However, would people from different culture respond with the same manner? Figure 4 shows the age-specific disability rate of 2 different definitions for the 3 countries. One is defined as severer 2 categories and the other is severer 3 categories. By definition, 3 categories disability rate is higher than 2 categories disability rate and it is the case for all 3 countries. However, the difference between the 2 and 3 categories rates are not very conspicuous; 2 categories disability rate of Brazil is higher than the 3 categories disability rate of Vietnam for up to 50 years old or so. It is a difficult task to draw the line but if it is difficult, then the merit and demerit of having the luxury of choices should be discussed, especially with the strong pressure of simplifying the census questionnaire.
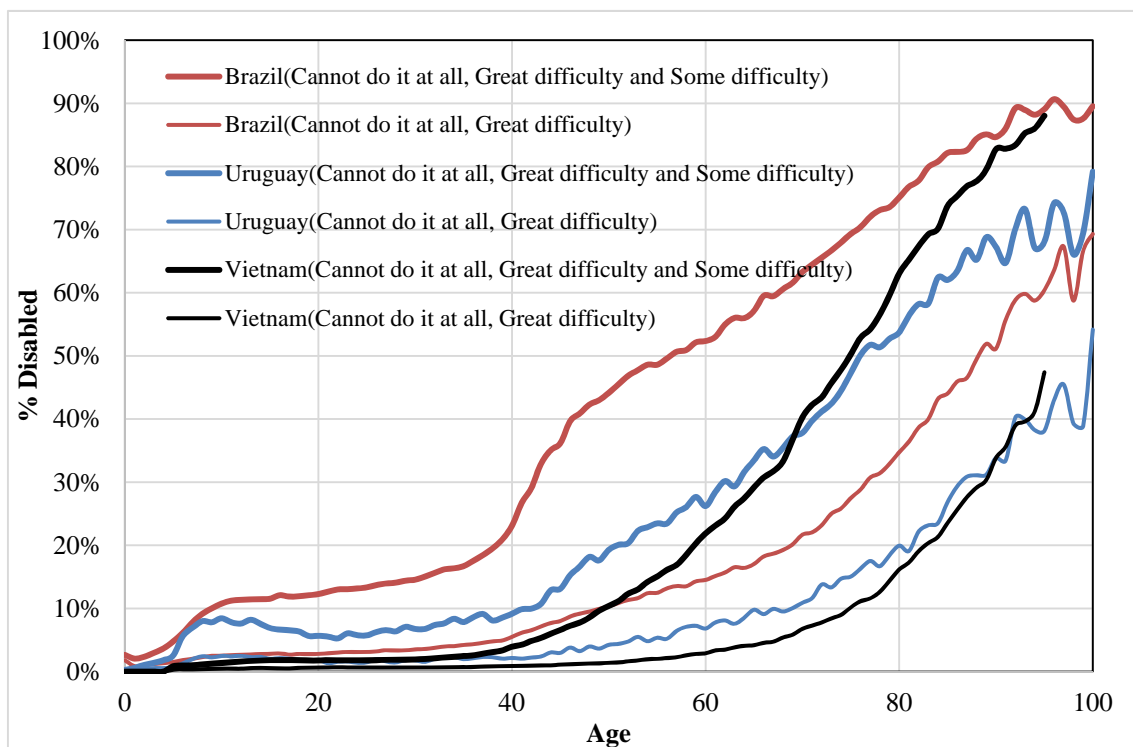

Figure 4   Age-specific disability rate with different definition
Source : Census microdata through IPUMS. The year of the census is listed in Annex Table 1.

The level of disability rate should be affected by the number of type of disabilities considered and its contents but it will be discussed elsewhere.

For now, the author finds no explanation for the high rates of Puerto Rico and Dominican Republic. It would need further investigation.

If we consider only the selected 13 countries, excluding from the original 29 countries the group of "low" countries and very high Puerto Rico and Dominican Republic, the disability rates can be internationally comparable. It seems essential that the disability question do not use filter question

and also do not label the question with the term "disability".

IV. Disability statistics by registration – the case of Japan

Unfortunately, no disability question is asked in Japanese Census. On the other hand, the disability statistics are available from sample surveys. The main survey is the Survey on Difficulties in Life (SDL[1]) which was conducted in 2011 by Ministry of Health, Labour and Welfare, replacing the Surveys on Persons with Physical/Intellectual Disability. It is a nationally representative household sample survey covering 4,500 census blocks. The questionnaire was distributed for those who are; a.holding disability certificate, b.receiving the payment for services and supports and c.considered themselves as having difficulties due to the developmental disorder, intractable diseases, chronic diseases, injuries or other reasons. The disability rate of each category is a. 3.7%, b.0.3%, c.1.0% and altogether 5.0%.

Another survey is the Comprehensive Survey of Living Conditions (CSLC) which has been conducted since 1985 by the Ministry of Health, Labour and Welfare. This is a general household survey, not specially designed for disability statistics, and it contains the question on ADL. All household members are asked if she/he needs help or to be watched, and if yes, 4 choices are to be made according to the level of independence; a.need help but can go out alone, b.independent at home but cannot go out alone, c.can sit up, d.bed-ridden. In 2013, the disability rate of each category is a. 1.9%, b.1.7%, c.0.6%, d.0.5% and altogether 4.7%.

Both surveys do not cover the population in facility such as long term care facilities or hospitals of which the number of people can be assessed alternatively by administrative data.

The disability rates obtained by 2 surveys are similar; 5.0% by SDL and 4.7% by CSLC. However, the age specific disability rates (Table 2) reveal the difference by age groups. As the age specific disability rate of category c of SDL is not available, when the rates of remaining category a+b of SDL and a+b+c+d of CSLC are compared, SDL rate is much higher (around double) than the CSLC rate for the age group of 30 to 69 years old and it is much lower than the CSLC rate for the age group older than 70 years. The SDL category a+b is equivalent to the rate of disability registration which is mostly targeted for those who are in working age. Thus, the old age disability rate of SDL is lower than the disability rate of CSLC, the proportion of people who need help which is not bound to an existing social security scheme. On the other hand, not all disabled people are dependent or needing help of others especially in the middle age (30-64 years old). It all depends on the definition of "disability" but one should be aware that the disability rate based on the registration would be strongly affected by the administrative procedures.

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[1] The English translation is not official.

Table 2 Disability rate by age group, SDL and CSLC, Japan

Age	SDL (a+b)	CSLC (a+b+c+d)
0-9	0.9%	1.2%
10-17	1.2%	1.2%
18-19	1.3%	1.1%
20-29	1.3%	1.1%
30-39	1.8%	1.0%
40-49	2.1%	1.0%
50-59	2.8%	1.4%
60-64	4.9%	2.1%
65-69	6.3%	3.5%
70+	11.5%	18.3%
Total	4.0%	4.7%

Source : Survey on Difficulties in Life (SDL) 2011, Comprehensive Survey of Living Conditions (CSLC) 2013, Ministry of Health, Labour and Welfare, Japan. CSLC rate is calculated by secondary usage of the survey microdata.

In any case, the two rates of disability are much lower than that of other countries of aged society such as Ireland or USA. The low rate of disability in Japan has been already observed (Katsumata 2008) but also one can deduce that the low rate of Japan is due to the existence of filter question and explicit use of the term Disability. In addition, major challenge in the future for the Japanese disability statistics is how to integrate the existing disability statistics with old-age disability.

V. Conclusion

It has been argued that due to the different definition of disability it is difficult to cross compare the disability rate among different countries. However, if certain conditions are met, disability rate can be comparable. These conditions include; do not explicitly use the term Disability or Handicap in the question read by the respondent. As disability rate increase sharply with age, the rate should be observed age-specifically and population ageing should be taken into account.

The disability statistics are important for various reasons; monitoring the UN Convention on the Rights of Persons with Disability, monitor the state of the elderly to ensure active ageing or determine the needs for social security or measure the efficacy of it. These different purposes might affect the definition of disability in creating the statistics. However, it is essential to assess the overall level of disability throughout the whole population as the primary information and it seems that the approach taken at present through census harmonization is the best solution to "realize the future we want".

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Annex Table 1 List of 29 countries which asked disability question in census

No	Country	Census Year	Base	Explicit *	Seeing	Hearing	Speaking	Intel./Mental	Physical	Selfcare/Part.	Disabled (%) (*Italic:Explicit*)
1	Bangladesh	2010	P	Yes	O	O	O	O	O		*1.4*
2	Brazil	2010	P		O	O		O	O		6.7
3	Burkina Faso	2006	P	Filter	O	O		O	O		*1.2*
4	Cambodia	2008	P	Yes	O	O	O	O	O		*1.4*
5	Dominican R.	2010	P		O	O	O	O	O	S	12.1
6	Ecuador	2010	P	Filter	O	O		O	O		*6.1*
7	Egypt	2006	P	Filter	O	O	O	O	O		*0.6*
8	El Salvador	2007	P		O	O	O	O	O	S	4.1
9	Fiji	2007	H		O	O	O	O	O	S	-
10	Ghana	2010	P	Yes	O	O	O	O	O		*3.0*
11	Indonesia	2010	P		O	O		O	O	S	4.3
12	Iran	2006	P	Yes	O	O	O	O	O		*1.5*
13	Ireland	2011	P		O	O		O	O	S/P	12.9
14	Kenya	2009	P	Yes	O	O	O	O	O	S	*0.9*
15	Liberia	2008	P	Filter							*3.1*
16	Malawi	2008	P	Yes	O	O	O		O		*3.9*
17	Mali	2009	P	Yes	O	O		O	O		*0.7*
18	Mexico	2010	P		O	O	O	O	O	S	5.2
19	Nicaragua	2005	H		O	O	O	O	O	S	-
20	Panama	2010	P		O	O	O	O	O		7.7
21	Peru	2007	H	Yes	O	O	O		O		-
22	Puerto Rico	2005	P		O	O		O	O	S/P	23.6
23	South Africa	2007	P	Filter	O	O	O	O	O		*4.0*
24	South Sudan	2008	P		O	O	O	O	O		5.1
25	Sudan	2008	P		O	O	O	O	O		4.8
26	USA	2010	P		O	O		O	O	S/P	12.4
27	Uruguay	2011	P		O	O		O	O		4.6
28	Viet Nam	2009	P		O	O		O	O		1.5
29	Zambia	2010	P	Filter	O	O	O	O	O		*2.0*

* "Explicit" column shows whether there is a filter question such as "are you disabled?" ("Filter") or the term "disability" or "handicap" is used in the questionnaire so that the respondent would read ("Yes").