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REGIONAL REPORT ON MEASURING DISABILITY

Overview of the disability measurement procedures in Latin America and the Caribbean

Task Force on Disability Measurement Statistical Conference of the Americas (SCA)

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INTRODUCTION

Quantifying persons with disability poses many challenges relating to the definition of disability adopted, the measurement instrument used, the aspects of disability being measured and the properties of the information sources available. Despite the increasing inclusion of persons with disabilities in Latin American and Caribbean information systems (particularly from the 2000 round of censuses), the conceptual, methodological and operational differences in the region's collection procedures make it difficult to quantify the situation properly, track its development and identify trends over time.

As these limitations apply to all countries worldwide, Article 31 of the Convention on the Rights of Persons with Disabilities (2006) deals with the gathering and dissemination of data and statistics on such matters. At the regional level, this situation was reflected in the conclusions of the Meeting of experts to define strategic priorities for the regional agenda on the situation of persons with disabilities (Santiago, 14 and 15 May 2013) and the implementation of a single system of information and identification for the population with disabilities to determine appropriate policy actions and services (ECLAC, 2013b). In response to these recommendations, the 7th Statistical Conference of the Americas of the Economic Commission for Latin America and the Caribbean (Santiago, 5 to 7 November 2013) approved the establishment of a Task Force comprising representatives from Belize, Brazil, Costa Rica and the Dominican Republic to coordinate the drafting of a regional report on the statistical information available in the countries of Latin America and the Caribbean and the difficulties encountered in assessing the status of persons with disabilities (for submission at the next meeting of the Executive Committee of the Statistical Conference of the Americas).

The Executive Committee should be able to use this information to identify requirements for strengthening national statistical offices, with a view to improving the quality of statistical data collection and providing relevant guidelines to the Task Force. The purpose is to implement the second part of the mandate received in November 2013, in order "to liaise with the member countries of the Washington Group on Disability Statistics and with the Pan American Health Organization/World Health Organization to look into avenues for collaboration and into the possibility of holding two subregional training workshops at national statistical offices in Latin America and the Caribbean in preparation for the next round of censuses" (ECLAC, 2014).

At the end of January 2014, a brief questionnaire on the availability of data on people living with some form of disability was sent to 42 Latin American and Caribbean countries. The questionnaire had two sections: one with basic questions on definitions and data availability, and another requesting information on the number of people living with some form of disability (in accordance with questions traditionally used in censuses and the questions proposed by the Washington Group on Disability Statistics). In total, 36 of the 42 countries provided information between March and May 2014. This survey was a partial reproduction of the one carried out in Caribbean countries in 2010 and Latin American countries in 2011/2012 (before being published in Chapter V of the *Social Panorama of Latin America 2012*, which dealt with the situation of persons with a disability in Latin America and the Caribbean) (ECLAC, 2013a). This 2014 version of the questionnaire also contained a new series of questions on possible additional sources of information, the dissemination of available data and the main difficulties in regularly collecting comparable and reliable statistics.

This document forms the first part of the regional report requested, with a view to analysing the qualitative information collected on the conceptual, methodological and institutional aspects of those processes. The data themselves will be presented in the second part of the final report to be submitted to

the 8th Statistical Conference of the Americas in the final quarter of 2014. This first part simply considers the overall figure and national prevalence rates of persons with disabilities, with a view to setting the context and providing examples.

The information provided by the national statistical offices of 17 Latin American countries and 19 Caribbean countries/territories is organized into three chapters. The first chapter opens with a brief account of the development of the concept of disability worldwide, and then reviews the degree to which measurement processes follow the international guidelines established by the Washington Group of the Statistical Commission of the United Nations, the World Health Organization International Classification of Functioning, Disability and Health (ICF) and the United Nations Guidelines and Principles for the Development of Disability Statistics. The second chapter describes the state of the art in the region's countries in terms of measuring disability, the use of the concept of disability, sources and categories of available data, organizational attributes of statistical collection institutions and public dissemination efforts. The third chapter analyses the main difficulties countries face in collecting information, and explores possible links between types of difficulty and the scope of data collected.

The first part of the regional report presented by the Task Force on Disability Measurement concludes by outlining the most relevant aspects of building integrated high-quality information systems.

I. INCLUSION OF INTERNATIONAL GUIDELINES IN DISABILITY MEASUREMENT PROCESSES IN LATIN AMERICAN AND CARIBBEAN COUNTRIES

A. DEVELOPMENT OF THE CONCEPT OF DISABILITY

The concept of disability at the basis of measurements of the situation of persons with disabilities has evolved considerably in recent decades. There has been a move away from the historical medical model that considered disability as a personal health problem directly caused by illness, disorder or an accident, and one that needed to involve medical treatment and individual rehabilitation to help people adapt to their new situation. This development has been reflected in a continuum of measurement proposals and models, and this process has gathered pace since the 1980 publication of the first International Classification of Impairments, Disabilities and Handicaps (ICIDH) by the World Health Organization (WHO). At the time, that publication fully reflected the biomedical model and linked physical and mental deficiencies, impairment and abnormality.

In 1997, WHO drafted a new proposal as a tangible reflection of the transition to the social model of disability, which considers the social integration of people suffering the impact of a disease (on the basis that the impact is not an attribute of the person but rather a set of alterations in the person's interaction with his or her environment) (ECLAC, 2013a). The approach proposed by WHO arose from the clash between the two models, and put forward a bio-psychosocial perspective that defines disability as a social and personal problem that requires not just medical and rehabilitation treatment but also support for social integration (that in turn requires changes to the environment and to the person). The impact of the disease is considered to be a complex interaction between health changes and contextual factors, such that interventions into one aspect may affect other related aspects. In 2001, this concept was refined by WHO with the publication of the International Classification of Functioning, Disability and Health (ICF), which provided a clear and coherent description of the biological, individual and social dimensions of disability.

According to information gathered by the Latin American and Caribbean Demographic Centre (CELADE)-Population Division of ECLAC, and subsequently by ECLAC itself when it collected data in 2010/2012 and in 2014, during the 1990s, census questions focused on the concept of sensory, motor or mental "impairments". A typical question of this nature would be: Do you suffer from any of the following impairments? With regard to the possible impairments, respondents could only answer Yes/No for total blindness, total deafness, muteness, disability/paralysis and mental impairment. By the 2000s, a shift had taken place in how the questions were designed and worded. Some countries had taken on board international recommendations that disability be perceived in terms of limitations and restrictions on social participation owing to contextual, environmental and personal factors rather than individual impairments. A number of Latin American countries made significant changes to their definitions: Brazil (2000), Colombia (2005), El Salvador (2007) and Peru (2007). In the Caribbean, Belize (2000), Trinidad and Tobago (2000), Antigua and Barbuda (2001), Dominica (2001) and Guyana (2002) also placed greater emphasis on limitations to participation in activities. Nonetheless, several countries in the region continued to focus on "impairments" (ECLAC, 2013a).

B. BRIEF QUESTIONNAIRE PRODUCED BY THE WASHINGTON GROUP

In order to bring developments in the conceptual framework into line with the collection of information on persons with disabilities worldwide, in 2002 the member countries of the United Nations Statistical Commission set up the Washington Group on Disability Statistics, to “provide basic necessary information on disability which is comparable throughout the world”. This was part of the follow-up to the United Nations International Seminar on Measurement of Disability, which in June 2001 recommended that principles and standard forms for indicators of disability be developed for use in censuses. There was a broad consensus on the need for population-based measures of disability for country use and for international comparisons (United Nations, 2011).

The most widely acknowledged or impressive achievement of the Washington Group was the drafting, pilot testing in various continents and promotion of a brief list of questions that can be used in censuses and surveys. This list includes questions on the level of severity of difficulties affecting six basic functions: sight, hearing, walking, cognitive faculties, self-sufficient personal care and communication. The questions were based on the model of disability from the International Classification of Functioning, Disability and Health of the World Health Organization (WHO), with an emphasis on their international comparability (United Nations, 2011). In Latin America, its proposal was assessed by the MERCOSUR countries in a joint pilot test in 2006 and by Uruguay in a pilot test on disability in 2008. These experiences, in addition to a number of regional activities linked to preparation of the 2010 census round, culminated in a minimum recommendation by the Latin American and Caribbean Demographic Centre (CELADE)-Population Division of ECLAC that comprised the following four domains (questions): Do you have difficulty seeing, even if wearing glasses or lenses? Do you have difficulty hearing, even if using a hearing aid? Do you have difficulty going up or down stairs? Do you have difficulty remembering, concentrating, making decisions or communicating? For each question, there are four possible responses depending on the degree of severity, namely: 1. Unable to do it at all; 2. Yes, a lot of difficulty; 3. Yes, some difficulty; 4. No, no difficulty (ECLAC, 2013a).

In Latin America and the Caribbean as a whole, the brief questionnaire has been applied in 21 countries (mainly as part of the 2010 round of censuses, except in Brazil where the relevant census was from 2000) (see tables 1a) and 1b)). Other countries implemented the questionnaire in representative surveys.

In Latin America, specific surveys were implemented in Argentina, 2002/3; Chile, 2004; and Peru, 2012, with household surveys conducted in Chile, 2011; Costa Rica, 2010 and 2013; Mexico 2012; and the Dominican Republic, 2013. With the exception of Cuba (2012), Ecuador (2010) and the Bolivarian Republic of Venezuela (2011), which continue to apply an impairments-based approach— all the countries that have already conducted their census for this decade used the new approach, based on difficulties or limitations in activities, and incorporated at least the four domains recommended by CELADE. However, only Brazil (2010), Paraguay (2012) and Uruguay (2011) included the four degrees of severity; Argentina (2010), the Plurinational State of Bolivia (2012), Costa Rica (2011), Mexico (2010) and Panama (2010) used yes/no responses. Some countries added other domains, such as difficulty using arms or legs (Costa Rica and Panama) or difficulty getting dressed, bathing or eating (Mexico).

In the Caribbean, two countries included the questions proposed by the Washington Group in their sample surveys: Bermuda (2007) and Guyana (2005). Of the 19 countries that contributed to this report, 10 implemented the brief questionnaire. Most of these used all six questions and the four levels of difficulty, while some introduced changes (such as Saint Lucia including separate questions on difficulties in self-care and the use of upper limbs). The countries that used the questions were Aruba (2010), Belize

(2010), Curaçao (2011), Grenada (2011), British Virgin Islands (2010), Jamaica (2011), Santa Lucia (2010), Sint Maarten (2011), Suriname (2012) and Trinidad and Tobago (2011). According to information provided by CELADE (ECLAC, 2013a), the questions were also included by Anguilla (2011), Antigua and Barbuda (2011), Dominica (2011) and Saint Vincent and the Grenadines (2011) (although the authors were unable to access that information).

C. INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

For the first time, the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO) established a multidimensional conceptual and methodological framework for the dialectical relationship between health and “health-related” states or “health and well-being” using standardized definitions and concepts that can be used to measure disability. These helped to improve the comparability of statistical data at the national and international levels.

The classification is organized around domains that are “sets of related physiological functions, anatomical structures, actions, tasks, areas of life, and external influences” related to the body and individual perspective by two basic lists: body structures and function, and participation activities (WHO, 2001). In the first list, impairment is a loss or abnormality in body structure or physiological function (impaired vision, hearing, speech, cognition and mental functions relating to mood, emotions and thought). In the area of activities and participation, “Difficulties or problems in these domains can arise when there is a qualitative or quantitative alteration in the way in which an individual carries out these domain functions” (difficulties or problems communicating, walking, climbing stairs or moving lower limbs; getting up, carrying, moving and using objects; self-care and relating to others).

Although the questions produced by the Washington Group were based on that Classification, interestingly the 21 countries using the questions and the 25 countries using the Classification do not always overlap as one might expect. In Latin America, 16 out of 17 countries reported using the Classification as a reference for defining the categories and levels of disability, while six described only applying the Classification in some cases. Of those 16, seven did not use the Washington Group questions in their most recent census (Bolivarian Republic of Venezuela, Colombia, Cuba, Ecuador, El Salvador and Guatemala) and Haiti. Haiti reported that it would do so in the next census scheduled for 2014). The only country not to use the Classification —the Plurinational State Bolivia, (2012)— did include the Washington Group questions in its most recent census, and this certainly represents progress (see table 1 a).

The situation in the Caribbean is even more confusing. While nine countries and territories reported using the Classification as a reference (with Montserrat using it only in some cases), four of these did not use the Washington Group questions in their 2010 round of censuses (Barbados, Bermuda, Turks and Caicos Islands and Montserrat). Of the 11 countries that did use the questions, six do not use the Classification to help define the categories and level of disability (Belize, Curaçao, Grenada, Sint Maarten and Trinidad and Tobago) or did not reply (British Virgin Islands) (see table 1 b). These facts point to the use of concepts and methodologies still being at an early stage, as they have not yet been consistently adopted as part of statistical production processes.

D. GUIDELINES AND PRINCIPLES FOR THE DEVELOPMENT OF DISABILITY STATISTICS

An analysis of the application of the Guidelines and Principles for the Development of Disability Statistics, published by the United Nations in 2001, reveals a slightly more organized landscape. The Guidelines were laid down by the UN Statistics Division, and are intended mainly for national statistical offices and other national statistics producers in order to guide their work in terms of the planning, gathering, processing, evaluation, tabulation and dissemination of statistics on persons with disabilities in surveys and censuses (United Nations, 2001). The Guidelines also recommend that questions on disability measurement be designed within the conceptual framework of the International Classification of Functioning, Disability and Health (ICF) (ECLAC, 2011).

In Latin America, 13 out of the 17 countries that report applying the Guidelines and Principles also apply the ICF guidelines (which represents greater coherence in the use of the two instruments). Four countries apply them only in some cases (Brazil, Costa Rica, Haiti and the Bolivarian Republic of Venezuela), two do not apply them (Plurinational State of Bolivia and Cuba), one did not respond (Panama) and Guatemala plans to apply them in the 2015 population census. The Plurinational State of Bolivia again uses the Washington Group questions but does not apply the Guidelines and Principles.

Cuba does not use either system, but reports partial usage of the ICF (which could be seen as the first steps in the process). In what could be a sign of improving national processes to measure disability, six countries did not use the Washington questions in their most recent censuses but do use the Guidelines and Principles plus the International Classification (Colombia, Ecuador, El Salvador, Guatemala and the Bolivarian Republic of Venezuela) or intend to in the next census (Haiti) (see table 1 a).

In the Caribbean, the application of the Guidelines is less widespread. Nine out of the 18 countries that replied to the question do apply the Guidelines and Principles: in at least some cases (this applies to four countries) or alongside the ICF (the following seven countries: Aruba, Barbados, Guyana, Turks and Caicos Islands, Jamaica, Montserrat and Saint Lucia). Unlike in Latin America, five countries that used the Washington Group questions do not apply the Guidelines and Principles (Belize, Curaçao, Grenada, Sint Maarten and Trinidad and Tobago) and two did not reply (British Virgin Islands and Suriname). In contrast, the Guidelines and Principles are the only instrument for standardizing disability measurement that have been implemented in the Bahamas and Saint Kitts and Nevis, while in Bermuda this applies to the ICF (see table 1b).

This range of situations in terms of the application of the various international recommendations makes it difficult to find a pattern that can contribute to the systematic implementation of disability measurement systems in a context where only eight Latin American countries (Argentina, Brazil, Chile, Costa Rica, Dominican Republic, Mexico, Paraguay and Peru) and four Caribbean countries (Aruba, Guyana, Jamaica and Saint Lucia) are currently applying all recommendations.

This issue will be revisited in Chapter III, which examines the main difficulties countries face in collecting statistical data.

Table 1a
LATIN AMERICA (17 COUNTRIES): DIFFICULTIES IN COLLECTING STATISTICAL DATA

Country	Application of international recommendations		Difficulties in collecting statistical data								
	Washington Group questions		ICF references	UN Guidelines and Principles	Lack of mandate	Lack of government interest	Lack of budget	Lack of qualified human resources	Validity of sample size	Lack of analytical capacity	Conceptual and operational difficulties
	Yes	Source									
Latin America											
Argentina	✓	ENDISC 2002/3	✓ ^a	✓							
Bolivia (Plurinational State of)	✓	Census 2012	No	No	✓						
Brazil	✓	Census 2000 and 2010	✓	✓ ^a							
Chile	✓	CASEN 2011	✓ ^a	✓	✓						✓
Colombia	No		✓	✓							
Costa Rica	✓	ENAHO 2010 and 2013	✓	✓ ^a			✓		✓		
Cuba	No		✓ ^a	No							✓
Ecuador	No		✓ ^a	✓					✓		✓
El Salvador	No		✓	✓							
Guatemala	No		✓ ^a	^b							
Haiti	No	^c	✓	✓ ^a							
Mexico	✓	Census 2010 and ENIGH 2012	✓	✓				✓			✓ ^d
Panama	✓	Census 2010	✓								
Paraguay	✓	Census 2012	✓	✓	✓					✓	
Peru	✓	ENEDIS 2012	✓	✓							
Dominican Republic	✓	Census 2010 and ENHOGAR 2013	✓	✓							
Venezuela (Bolivarian Republic of)	No		✓ ^a	✓ ^a							✓ ^e
Latin America total	10		16	13	3	1	8	2	3	2	5

Source: Economic Commission for Latin America and the Caribbean (ECLAC), based on replies to surveys that the Commission carried out in 2014 on disability measurement in Latin America and the Caribbean.

Note: All abbreviations refer to representative surveys (either household or specific ones).

^a Applied in some cases.

^b The country plans to apply the United Nations Guidelines and Principles for the Development of Disability Statistics in the 2015 census.

^c The country plans to use the Washington Group questions in the 2014 census.

^d Lack of statistical projects incorporating that issue.

^e Responses through a third party (which may affect the information in terms of under-reporting or over-reporting). This highlights the need for census questionnaires to include other questions to clarify/control for the informer's response.

Table 1b
CARIBBEAN (19 COUNTRIES AND TERRITORIES): DIFFICULTIES IN COLLECTING STATISTICAL DATA

Country	Application of international recommendations				Difficulties in collecting statistical data						
	Washington Group questions		ICF references	UN Guidelines and Principles	Lack of mandate	Lack of government interest	Lack of budget	Lack of qualified human resources	Validity of sample size	Lack of analytical capacity	Conceptual and operational difficulties
	Yes	Source									
The Caribbean											
Aruba	✓	Census 2010	✓ ^a	✓		✓					
Bahamas	No		✓	✓							
Barbados	No		✓	✓			✓				
Belize	✓	Census 2010	No	No	✓	✓	✓	✓		✓	
Bermuda		^b	✓	No		✓					
Curaçao	✓	Census 2011	No	No		✓					✓ ^c
Grenada	✓	Census 2011	No	No		✓					
Guyana	✓	Specific survey 2005	✓	✓		✓					
Cayman Islands	No		No	No	✓	✓					
Turks and Caicos Islands	No	^d	✓ ^a	✓	✓ ^r	✓					✓
British Virgin Islands	✓	Census 2010 ^e									
Jamaica	✓	Census 2011	✓	✓ ^a		✓					
Montserrat	No		✓ ^a	✓ ^a		✓				✓	
Saint Kitts and Nevis	No		No	✓ ^a	✓	✓				✓	
Sint Maarten	✓	Census 2011	No	No		✓					✓
Saint Lucia	✓	Census 2010	✓	✓		✓			✓		
Suriname	✓	Census 2012	✓								n/a
Trinidad and Tobago	✓	Census 2011	No	No	✓						
The Caribbean total	11		9	9	5	2	12	6	2	3	2
Regional total	21		25	22	8	3	20	8	5	5	7

Source: Economic Commission for Latin America and the Caribbean (ECLAC), based on replies to surveys that the Commission carried out in 2014 on disability measurement in Latin America and the Caribbean.

^a Applied in some cases.

^b Seniors Test for Ageing Trends and Services Survey, 2007. Information available only for people aged 60 and over.

^c Lack of cooperation among various relevant counterparts.

^d Country used the brief questionnaire of the Washington Group in 2014 but did not specify the relevant survey.

^e Statistical information from the 2010 census is not yet available.

^f The mandate is limited to information collected during the census.

E. IMPORTANCE OF METHODOLOGIES USED

The conceptual and methodological differences that we have just reviewed have a direct impact on the figures, as shown in available statistical data on disability in the region's countries —hence the need to exercise caution when it comes to making comparisons.

Much of the following information on the scale and level of disability in the region's countries comes from the 2010 round of censuses, which incorporated questions on disability (Argentina, Bolivia (Plurinational State of), Brazil, Costa Rica, Cuba, Ecuador, Mexico, Panama, Paraguay, Uruguay and Venezuela (Bolivarian Republic of) in Latin America; and Aruba, Bahamas, Barbados, Belize, Cayman Islands, Curaçao, Jamaica, Montserrat, Saint Lucia, Sint Maarten, Suriname, Trinidad and Tobago and Turks and Caicos Islands in the Caribbean).

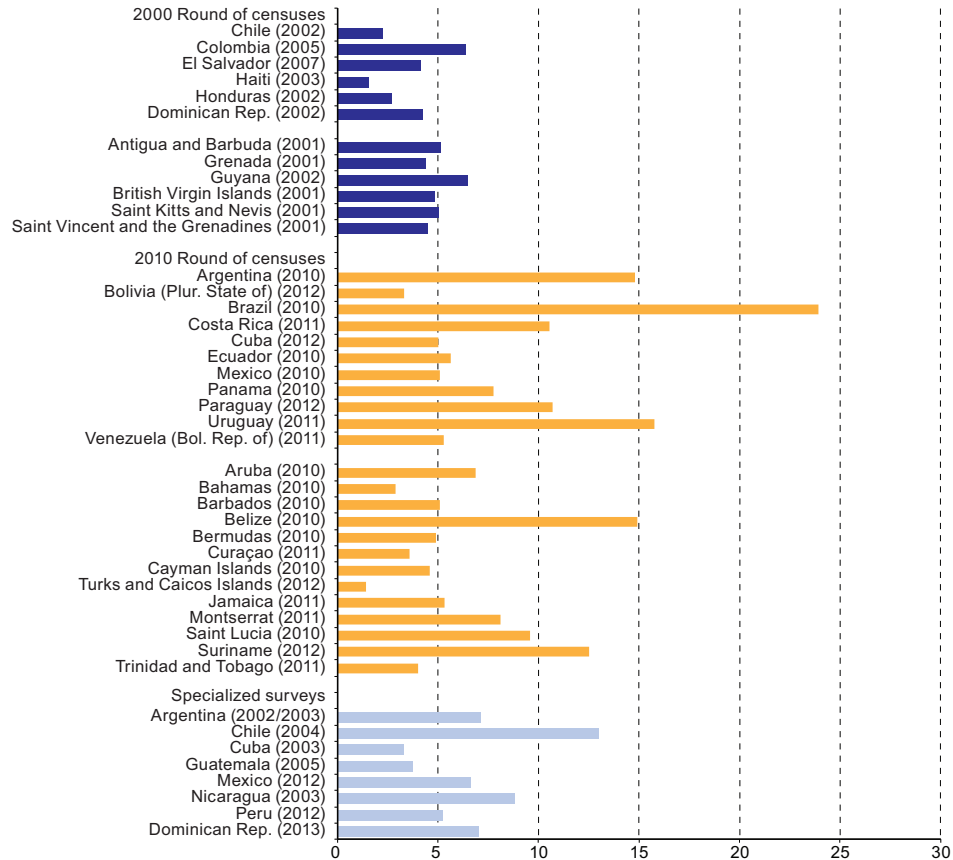
The 2000 round of censuses has been used for the region's countries that have not yet applied or completed the census processing for the 2010 round (Chile, Colombia, Haiti and Honduras in Latin America; and Antigua and Barbuda, British Virgin Islands, Grenada, Guyana, Saint Kitts and Nevis and Saint Vincent and the Grenadines in the Caribbean). Census information has been supplemented by data from household surveys (Dominican Republic and Mexico) and specialized surveys (Argentina, Chile, Cuba, Guatemala, Nicaragua and Peru), where the latter were more up to date than the most recent census, or in order to further illustrate the impact of source type on the disability prevalence estimates presented in figure 1.

It is possible to use this information to estimate that the number of people living with some kind of disability in Latin America and the Caribbean between 2001 and 2013 was over 70 million (or 12.5% of total regional population, 12.6% of the population of Latin America and 6.1% in Caribbean countries) (see table 2). It is striking that, compared with the figures from the Social Panorama of Latin America 2012 (and certainly due to the inclusion of more recent sources from various countries), the region's total number of persons with disabilities has increased by more than 4.5 million (from 66,121,596 people in 2011 to 70,666,206 people). Since the previous information was collected in 2010-2012, this is the equivalent of a 0.2 percentage point increase in Latin America (12.4% in 2012) and a 0.7 percentage point increase in the Caribbean (5.4% in 2012). In the latter case, this is a rise of almost 13%.

An analysis of figure 1 clearly reveals the surge in disability rates captured by the 2010 round of censuses compared with the 2000 round (with the latter being below the collection level of sample surveys). However, there remain significant variations in disability prevalence rates among countries (even in the 2010 round). Many of these large gaps are difficult to explain, such as those between the 3.3% in the Plurinational State of Bolivia and 23.9% in Brazil (for Latin America) and 1.4% in the Turks and Caicos Island and 14.9% in Belize for the Caribbean. Out of these four countries, Turks and Caicos was the only one not to use the Washington Group brief questionnaire in its most recent census.

Even among countries using the same measurement tool, a detailed breakdown of census bulletins provides some clues about the reasons for such differences. Bulletins reflect the different interpretations of the methodological proposal of the Washington Group, particularly in terms of the four levels of severity: 1. Unable to do it at all; 2. Yes, a lot of difficulty; 3. Yes, some difficulty; 4. No, no difficulty.

Figure 1
LATIN AMERICA AND THE CARIBBEAN (38 COUNTRIES): PERCENTAGE OF PERSONS WITH DISABILITIES, BY SOURCE



Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of Latin America: Argentina: National Survey on Persons with disabilities (ENDI), 2002/2003 and National Population, Household and Housing Census, 2010; Bolivia (Plurinational State of): Population and Housing Census, 2012; Brazil: Population Census, 2010; Chile: 17th National Population Census, 6th Housing Census, 2002, and National Disability study (ENDISC), 2004; Colombia: Population and Housing Census, 2005; Costa Rica: 10th National Population Census and 6th Housing Census, 2011; Cuba: Psychopedagogical, Social and Clinical-Genetic Study of Persons with disabilities, 2003 and Population and Housing Census, 2012; Dominican Republic: 8th National Population and Housing Census, 2002 and National Multipurpose Household Survey (ENHOGAR), 2013; Ecuador: Population and Housing Census, 2010; El Salvador: 6th Population Census and 5th Housing Census, 2007; Guatemala: National Disability Survey (ENDISC), 2005; Haiti: General Population and Housing Census; Honduras: 11th National Population Census and 6th Housing Census, 2002; Mexico: Population and Housing Census, 2010 (extended questionnaire) and National Household Income and Spending Survey (ENIGH), 2012; Nicaragua: National Disability Survey (ENDIS), 2003; Panama: Population and Housing Census, 2010; Paraguay: National Population and Housing Census, 2012; Peru: Specialized National Disability Survey, 2012; Uruguay: National Population Census, 2011; Venezuela (Bolivarian Republic of): Population and Housing Census, 2011; The Caribbean: Population and Housing Census of: Antigua and Barbuda (2001); Aruba (2010); Bahamas (2010); Barbados (2010); Belize (2010); Bermuda (2010); British Virgin Islands (2001); Cayman Islands (2010); Curaçao (2011); Grenada (2001); Guyana (2002); Jamaica (2011); Montserrat (2011); Saint Kitts and Nevis (2001); Saint Vincent and the Grenadines (2001); Saint Lucia (2010); Sint Maarten (2011); Suriname (2012); Trinidad and Tobago (2011); and Turks and Caicos Islands (2012).

Table 2
LATIN AMERICA AND THE CARIBBEAN (39 COUNTRIES): PERSONS WITH DISABILITIES, 2001-2010
(Absolute numbers and percentages)

Country	Year	Persons with disabilities	Total population	Percentage
Latin America				
Argentina	2010	5 114 190	34 556 941	14.8
Bolivia (Plurinational State of)	2012	326 361	10 027 254	3.3
Brazil	2010	45 606 048	190 691 024	23.9
Chile	2002	334 377	15 116 435	2.2
Colombia	2005	2 624 898	41 468 384	6.3
Costa Rica	2011	452 849	4 301 712	10.5
Cuba	2012	556 317	11 167 325	5.0
Ecuador	2010	816 156	14 483 499	5.6
El Salvador	2007	235 302	5 744 113	4.1
Guatemala (6 years and over)	2005	401 971	10 758 805	3.7
Haiti	2003	124 534	8 373 750	1.5
Honduras	2002	177 516	6 697 916	2.7
Mexico	2012	7 767 142	117 449 649	6.6
Nicaragua (6 years and over)	2003	461 000	5 267 715	8.8
Panama (Washington Group Qs)	2010	263 924	3 405 813	7.7
Paraguay	2012	713 972	6 672 631	10.7
Peru	2012	1 575 402	30 274 623	5.2
Dominican Republic	2013	708 597	10 177 007	7.0
Uruguay	2011	517 771	3 285 877	15.8
Venezuela (Bolivarian Republic of)	2011	1 454 845	27 227 930	5.3
Latin America total		70 233 172	557 148 402	12.6
The Caribbean				
Antigua and Barbuda	2001	3 918	76 886	5.1
Aruba	2010	6 954	101 002	6.9
Bahamas	2010	10 138	351 461	2.9
Barbados	2010	11 546	226 193	5.1
Belize	2010	47 995	322 453	14.9
Bermuda	2010	3 174	64 237	4.9
Curaçao	2011	5 432	150 563	3.6
Grenada	2001	4 497	103 133	4.4
Guyana	2002	48 419	751 216	6.4
Cayman Islands	2010	2 475	53 834	4.6
Turks and Caicos Islands	2012	365	26 553	1.4
British Virgin Islands	2001	1 107	23 161	4.8
Jamaica (5 years and over)	2011	143 625	2 697 983	5.3
Montserrat	2011	401	4 922	8.1
Saint Kitts and Nevis	2001	2 328	46 325	5.0

Table 2 (concluded)

Country	Year	Persons with disabilities	Total population	Percentage
Saint Lucia	2010	15 866	165 595	9.6
Saint Vincent and the Grenadines	2001	4 717	106 253	4.4
Suriname	2012	67 835	541 638	12.5
Trinidad and Tobago	2011	52 242	1 322 546	4.0
The Caribbean total		433 034	7 135 954	6.1
Regional total		70 666 206	564 284 356	12.5

Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of Latin America: Argentina: National Population, Household and Housing Census, 2010; Bolivia (Plurinational State of): Population and Housing Census, 2012; Brazil: Population Census, 2010; Chile: 17th National Population Census and 6th Housing Census, 2002; Colombia: Population and Housing Census, 2005; Costa Rica: 10th National Population Census and 6th Housing Census, 2011; Cuba: Population and Housing Census, 2012; Dominican Republic: National Multipurpose Household Survey (ENHOGAR), 2013; Ecuador: Population and Housing Census, 2010; El Salvador: 6th Population Census and 5th Housing Census, 2007; Guatemala: National Disability Survey (ENDISC), 2005; Haiti: General Population and Housing Census, 2003; Honduras: 11th National Population Census and 6th Housing Census, 2002; Mexico: National Household Income and Spending Survey (ENIGH), 2012; Nicaragua: National Disability Survey (ENDIS), 2003; Panama: Population and Housing Census, 2010; Paraguay: National Population and Housing Census, 2012; Peru: Specialized National Disability Survey, 2012; Uruguay: National Population Census, 2011; Venezuela (Bolivarian Republic of): Population and Housing Census, 2011; The Caribbean: Population and Housing Census of: Antigua and Barbuda (2001); Aruba (2010); Bahamas (2010); Barbados (2010); Belize (2010); Bermuda (2010); British Virgin Islands (2001); Cayman Islands (2010); Curaçao (2011); Grenada (2001); Guyana (2002); Jamaica (2011); Montserrat (2011); Saint Kitts and Nevis (2001); Saint Lucia (2010); Saint Vincent and the Grenadines (2001); Sint Maarten (2011); Suriname (2012); Trinidad and Tobago (2011); and Turks and Caicos Islands (2012);

For instance, even though the Plurinational State of Bolivia included the six Washington Group questions in its 2012 census, they simply required “yes/no” answers without specifying level of difficulty (which means that only persons with severe disabilities would respond “yes”). Furthermore, persons with disabilities were assigned a code linking them to the population module and its characteristics. The link was not always activated when a variable such as age and/or sex was omitted (which could have resulted in collection gaps).

In Brazil, the four options on level of severity were included on the bulletin, which provides a plausible explanation for the large difference in people declaring a disability (the highest in the region). The same was true of two Caribbean countries, as the 2012 Turks and Caicos census used traditional census questions based on the medical model (not considering problems in participating in society) with yes/no answers, while the 2010 Belize census gave the option of the four levels of severity.

One example of the problems of deciding whether to incorporate the four levels of severity of disability was the processing of the 2010 census results in Saint Lucia (as reported by the Department of Statistics to the Task Force). The census bulletin used the six questions from the brief questionnaire (dividing one into two as previously mentioned), as well as the four levels of severity. The subsequent compilation of the responses resulted in a disability prevalence rate of 36.2% of the population. Recalculating the figures on the basis of those with moderate or severe difficulties (without including “some” difficulty) reduced the disability rate to 9.2% —which is still very high compared with other Caribbean countries.

The latter figure was supplied for this report. However, this example strikingly shows the importance for the region's countries of reaching agreement on which levels of severity to use when it comes to making comparisons and identifying support requirements within the population. The example also demonstrates how important it is to collect information on the four levels of severity (even if only rates of moderate and severe difficulty are cited when it comes to publication). This will ensure availability of all information that may prove useful for public policymaking, as well as information for assessing future service and welfare needs (as people with "some" difficulty are more likely to have severe difficulty in the future than those with "none").

II. STATE OF THE ART IN DISABILITY MEASUREMENT IN THE REGION'S COUNTRIES

A. USE OF THE CONCEPT OF DISABILITY IN THE REGION'S MEASUREMENT PROCEDURES

Above and beyond the international guidelines that the region's countries recognize as valid and use in their disability-measurement processes, it is vital to consider the definition of disability that countries themselves use as a conceptual basis for compiling national statistics. Interestingly, not all countries can clearly identify which definition they use (particularly in the Caribbean). Of the 36 countries that responded to the request from the SCA's Task Force, four simply refer to the use of the Washington Group questions (Brazil, Curaçao, Jamaica and Sint Maarten) while three did not send the information (despite the requests) (Grenada, Turks and Caicos Islands and Saint Vincent and the Grenadines).

The following operational classification was established for the definitions of disability used by national statistical offices:

- 1) The *bio-medical model*, which only refers to health impairments that prevent people from carrying out "normal" daily activities, with no measurement of limitations due to the environment. This is in the spirit of the 1980 International Classification of Impairments, Disabilities and Handicaps (ICIDH)
- 2) The *bio-psychosocial model* endorsed by the 2001 International Classification of Functioning, Disability and Health (ICF) and the Washington Group brief questionnaire. Although this does refer to limitations on participation, it concerns mainly the daily activities relating to self-care, education, work and recreation (with considerable emphasis on the medical situation).
- 3) The *social model*, which refers mainly to the exercise of human rights and the full and effective inclusion in society in equal conditions to other people.

In table 3 below, the 33 countries are fairly evenly spread in terms of the three models. Comparing replies with those received during the first ECLAC study in 2010/2012 shows that four countries have "progressed" to the next model:¹ Jamaica towards the bio-psychosocial model; and Ecuador, Haiti and Trinidad and Tobago towards the social model (in the last two cases, the definition is not yet being applied and will be used in the next round of data collection). Assuming that this constitutes progress, Caribbean countries appear to be remaining within the parameters of the bio-psychosocial model (7 out of 16), whereas 50% of Latin American countries (9 out of 17) are adopting the rights-based approach within the social model.

¹ These countries are indicated in bold within the disability definition they are currently using.

Table 3
**LATIN AMERICA AND THE CARIBBEAN (33 COUNTRIES):
 DEFINITION USED TO COLLECT STATISTICAL INFORMATION**

Models / References	Reference to ICIDH/ICD-10, individual impairments or limitations in daily life	Reference to the ICF or Washington Group questions	Reference to exercise of participation and/or the guarantee of rights
Bio-medical model (12 countries)	Latin America (6 countries): Bolivia (Plurinational State of) (2012), Cuba (2012), Ecuador (2001), Guatemala (2005), Haiti (2003), Panama (2010)		
	Caribbean (6 countries): Aruba (2010), Barbados (2010), Guyana (2002), Jamaica (2001), Montserrat (2011), Trinidad and Tobago (2011)		
Bio-psychosocial model (11 countries)		Latin America (4 countries): Argentina (2010), Brazil (2010), Dominican Republic (2013), Paraguay (2012)	
		Caribbean (7 countries): Belize (2010), British Virgin Islands (2001), Cayman Islands (2010), Curaçao (2011), Jamaica (2011) ^a , Sint Maarten (2011), Suriname (2012)	
Social model (14 countries)			Latin America (9 countries): Chile ^b , Colombia (2005), Costa Rica (2011), Ecuador (2010) , El Salvador (2007), Haiti ^b , Mexico (2012), Peru ^b , Venezuela (Bolivarian Republic of) (2011)
			Caribbean (5 countries): Bahamas (2010), Bermuda (2010), Saint Kitts and Nevis (2001), Saint Lucia (2010), Trinidad and Tobago ^b

Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

Note: Countries are indicated in bold when the definition they use for collecting statistics has changed since the last ECLAC study (2010 for the Caribbean and 2011 for Latin America).

^a The 2011 census used Washington Group questions, but the previous definition of disability was not used (and was not replaced with another).

^b Definition that will be used in the next data collection exercise that was being prepared when this survey was conducted.

A more refined analysis does, however, reveal discrepancies whereby the models of disability framing the operational definition (see annex 2) clash with the questions used in the national survey (see tables 1 a) and b)). For instance, there are two types of discrepancy in the use of Washington Group questions alongside a definition of disability that is lifted straight from the bio-medical model (in the Plurinational State of Bolivia and Panama in Latin America; and Aruba, Guyana and Trinidad and Tobago in the Caribbean). The other type of discrepancy is when the definition used comes from the social model, while the census bulletin questions are traditional ones based solely on impairment (Colombia, Ecuador, El Salvador and the Bolivarian Republic of Venezuela in Latin America; and Bahamas and Saint Kitts and Nevis in the Caribbean). This points to a lack of conceptual and methodological clarity, which will invariably have major implications when it comes to analysing statistical data and disseminating results, thereby restricting the benefits of the information collected for public policymaking and in terms of appropriately identifying the service needs of persons with disabilities.

B. INFORMATION SOURCES AVAILABLE AT THE NATIONAL LEVEL

In all countries worldwide, the main sources of information on people are population and housing censuses, household surveys and administrative records. Given that population censuses are a highly valued source of data thanks to their universal coverage, for decades they have been the source of choice for introducing questions on the situation of persons with disabilities (in order to establish prevalence rates of persons with disabilities, analyse their demographic and socioeconomic characteristics and identify their health and social requirements) (Schkolnik, 2010). However, censuses have the limitation of only being carried out once every 10 years, combined with the even more important factor of not including people who do not live in private residences (such as older adults in hospices, hospitals and care homes) —which means there is a risk of significantly underestimating the number of people living with some form of disability (ECLAC, 2011). Representative surveys and administrative records collect broader and more detailed information on the specific situation of persons with disabilities and their characteristics.

The information received from the 36 countries that replied to the SCA Task Force shows that all of them had collected statistical data on the situation of persons with disabilities in their most recent population and housing censuses (with 24 countries having completed the 2010 round of censuses). Furthermore, over the past decade 18 countries have carried out representative (sample) surveys including questions or modules on disability or conducted a specific survey on the subject. Two countries (one in Latin American and one in the Caribbean) also carried out more limited surveys that uncovered very detailed information on certain groups, such as Peru's 2012 Census on persons with disabilities in the Department of Tumbes, which is the country's main political and administrative division out of 24 departments; and Bermuda's 2009 National Survey of People who are Blind/ Visually Impaired (see table 4).

The vast majority of specific surveys have been implemented by national statistical offices, as is the case for household and multipurpose surveys, as well as censuses. In some cases, however, they have been implemented in conjunction with the national mechanism for monitoring the Convention on the Rights of Persons with Disabilities (Chile, Guatemala and Peru in Latin America; and Aruba and Trinidad and Tobago in the Caribbean). These national mechanisms led the process in Barbados, Bermuda and Guyana and for the Census of Persons with disabilities in the Peruvian Department of Tumbes.

Table 4
**LATIN AMERICA AND THE CARIBBEAN (36 COUNTRIES):
 AVAILABLE SOURCES OF INFORMATION**

Country	National registers	Administrative records	Censuses ^a	Sample surveys	Other
Argentina	√	√	2001	√	
Bolivia (Plurinational State of)	√	√	2012		
Brazil		√	1872	√	
Chile			2002	√	
Colombia	√	√	2005		
Costa Rica	√	√	2000	√	
Cuba			2012		
Ecuador			2001	√	
El Salvador			2007		
Guatemala			2002	√	
Haiti			2003	^b	
Mexico			2000	√	
Panama			1990	√	
Paraguay			1982	√	
Peru	√	√	1940	√	√
Dominican Republic		√	1920	√	
Venezuela (Bolivarian Republic of)	√	√	2001		
Latin America total	6	8	17	11	1
Aruba			1981	√	
Bahamas			2000		
Barbados	√	√	1990	√	
Belize			1991		
Bermuda			1991	√	√
Curaçao			1992		
Grenada			2001		
Guyana	√	√	2002	√	
Cayman Islands			1999		
Turks and Caicos Islands	√		2012		
British Virgin Islands			2001		
Jamaica			2001		
Montserrat			2001		
Saint Kitts and Nevis			2001		
Sint Maarten			2011	^c	
Saint Lucia	√		2001		
Saint Vincent and the Grenadines			2001		
Suriname	√		2012	√	
Trinidad and Tobago	√		2000	√	
The Caribbean total	6	2	19	7	1
Regional total	12	10	36	18	2

Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

^a Date of first census to collect information on disability.

^b The information collected by the 2012 Post-Earthquake Living Conditions Survey (ECVMAS) is not representative of the disabled population due to issues with the sample size.

^c Questions on disability will be included in the Health Survey "How Healthy is Sint Maarten?", scheduled for 2015.

Before the 2010 round of censuses, representative surveys were the first to highlight the high percentage of persons with disabilities to the public and decision-makers (see figure 1). This provided the motivation and interest in improving the collection of such data in population censuses. While sample surveys are very valuable, in that they offer an in-depth exploration of various aspects and needs of

persons with disabilities, population censuses remain the primary instrument of measuring disability as they provide a more precise idea of scale by counting and locating everyone with a disability. Censuses also enable data to be disaggregated by variables such as sex, age, ethnicity and marital status, as well as level of integration into the country's social and economic life based on level of education, employment status, type of employment, income bracket and access to social protection.

Only a third of countries providing information on information sources available at the national level also have records of people disabilities and their needs, either on a national register (as in 12 out of 36 countries) or administrative records maintained by various disability service providers (as in 10 out of 36 countries). These sources are extremely important, as those that exist provide information used to propose policies and programmes. It should be pointed out that the information from administrative records is limited to the scale, state and demand for services of people attending care centres (which makes it impossible to use the data to make estimates concerning the population as a whole) (Alm eras et al, 2002).

Given that the main purpose of the administrative records of public bodies is for their own internal management requirements, it is not feasible to use these data to measure changes in demand for services. Although the information received by the Task Force cannot be used to form an opinion on the state of current records, the limited information from national statistical offices replying to the ECLAC survey suggests that, while they are used in eight Latin American countries (Argentina, Bolivia (Plurinational State of), Brazil, Colombia, Costa Rica, Dominican Republic, Peru and Venezuela (Bolivarian Republic of) and two Caribbean countries (Barbados and Guyana), the information is scant and not based on homogenous collection or validation procedures among institutions. According to one of the Latin American national statistical offices, the information is even considered somewhat unreliable. It should be pointed out that, in order to be statistically useful, information recorded must be systematically and consistently transferred to a database for regular processing, based on standardized criteria relating to the concept of disability. This helps the data to be comparable among services (Alm eras et al, 2002).

One illustrative example is Argentina, where the National Institute of Statistics and Censuses (INDEC) carefully manages the content of administrative records on persons with disabilities from the Ministry of Health's National Rehabilitation Service, the Ministry of Education's National Directorate of Information and Evaluation of Educational Quality, the Ministry of Transport, the National Women's Council, the National Institute to Combat Discrimination, Xenophobia and Racism, Public Administration and the Ministry of Labour. The other country to have made progress is Brazil, thanks to the administrative records kept in three ministries of vital importance for monitoring the situation of persons with disabilities: Ministry of Labour and Employment, Ministry of Social Protection and Ministry of Health.

A national register includes background on persons with disabilities so that they can access a series of benefits, ideally in parallel with the administrative records of other government bodies. According to the information received by the Task Force, this type of record only exists in six Latin American countries (Argentina, Bolivarian Republic of Venezuela, Colombia, Costa Rica, Peru and Plurinational State of Bolivia) and six Caribbean countries (Barbados, Guyana, Saint Lucia, Suriname, Trinidad and Tobago and Turks and Caicos Islands). Other countries refer to a similar record in forms that should be further explored. All of the above points to the clear lack of an integrated information system at the national level.

In any event, the countries implementing some form of register are also those making the greatest effort to collect information overall: the six Latin American countries to have created a national register are part of the eight that keep administrative records (three of which have also carried out sample surveys: Argentina, Costa Rica and Peru). In the Caribbean, Barbados and Guyana are two countries applying the

same integrated efforts to collect information. Suriname and Trinidad and Tobago have similar intentions, and just need to create administrative records in the various ministries (see table 4).

C. CATEGORIES OF DATA AVAILABLE AT THE NATIONAL LEVEL FOR PUBLIC POLICYMAKING

The quality of any country's information system is directly reflected in the range of data categories available for the subsequent formulation of public policies, programmes and services. According to the United Nations Principles and Recommendations for Population and Housing Censuses formulated by the Statistical Commission (United Nations, 2007), the collection of disability data must include a series of variables to determine the key characteristics of persons with disabilities, as well as relevant variables on their socioeconomic situation (ECLAC, 2011), with a view to: planning programmes and services, monitoring selected aspects of national disability trends and evaluating the impact of sectoral policies and social programmes on equal opportunities for persons with disabilities (Schkolnik, 2010).

While preparing this regional report, the Task Force identified a series of 13 variables that are sufficiently broad in scope to provide all the information needed to respond to United Nations recommendations, while also highlighting the situation of people with disability alongside other sources of discrimination based on age, sex, poverty, area of residence and ethnicity. The request for information also considered availability for nationwide dissemination, thereby ensuring that it was available for use by public policymakers. The selected variables were as follows:

- Types of disability and limitations
- Severity of disability
- Age
- Age of onset of disability
- Rural/urban resident
- Ethnic or racial (in the Caribbean) background
- Marital status
- Level of education
- Employment status
- Type of employment
- Income bracket
- Access to social security/protection
- Origin/cause of disability

Table 5 below shows the availability of these data categories at the national and regional levels. The only information provided by all 36 countries that replied to the Statistical Conference's request was data on age and type of disability (not always disaggregated by sex) (see figure 2). This was followed by the level of education and employment status (available in 34 countries), type of employment (28 countries), area of residence (26 countries), marital status (25 countries), ethnic/racial background (24 countries), income bracket and origin of disability (21 countries). Information with a lower level of availability (from fewer than half the national statistical offices) included variables on: access to social protection/security (16 countries), severity of disability (14 countries) and the age of onset of disability (13 countries)—which are all crucial when it comes to evaluating care and welfare service requirements.

Table 5
LATIN AMERICA AND THE CARIBBEAN (36 COUNTRIES): CATEGORIES OF DATA AVAILABLE

Country	Type of disability	Severity of disability	Age	Age of onset	Area of residence	Ethnic/racial background	Marital status	Level of education	Employment status	Type of employment	Income bracket	Social protection	Origin of disability
Argentina	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	No	✓	✓
Bolivia (Plurinational State of)	✓	No	✓	No	✓	✓	✓	✓	✓	✓	No	No	No
Brazil	✓	✓	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	No
Chile	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Colombia	✓	No	✓	✓	✓	✓	✓	✓	No	No	No	✓	✓
Costa Rica	✓	No	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	No
Cuba	✓	No	✓	No	✓	No	No	No	✓	No	No	✓	No
Ecuador	✓	✓	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	✓
El Salvador	✓	No	✓	No	✓	✓	No	✓	✓	✓	No	No	No
Guatemala	✓	No	✓	✓	✓	✓	No	✓	✓	✓	✓	No	✓
Haiti	✓	No	✓	No	✓	No	✓	✓	✓	✓	No	No	No
Mexico	✓	No	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	✓
Panama	✓	No	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	No
Paraguay	✓	S	✓	No	✓	✓	No	✓	✓	No	No	No	✓
Peru	✓	✓	S	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Dominican Republic	✓	No	✓	✓	✓	No	No	✓	✓	✓	No	No	S
Venezuela (Bolivarian Republic of)	✓	No	✓	No	S	No	S	✓	S	S	No	No	No
Latin America total	17	6	17	6	17	13	12	16	17	14	8	10	9
Aruba	✓	No	✓	No	No	No	No	S	S	S	S	No	S
Bahamas	✓	No	✓	S	✓	S	✓	✓	✓	✓	✓	No	✓
Barbados	✓	No	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	✓
Belize	✓	✓	✓	No	✓	✓	✓	✓	No	No	No	No	No
Bermuda	✓	✓	✓	✓	No	✓	✓	✓	✓	✓	✓	✓	✓
Curaçao	✓	✓	✓	No	No	S	✓	✓	✓	✓	✓	No	No
Grenada	✓	✓	✓	S	No	No	No	S	S	S	S	No	S

Table 5 (concluded)

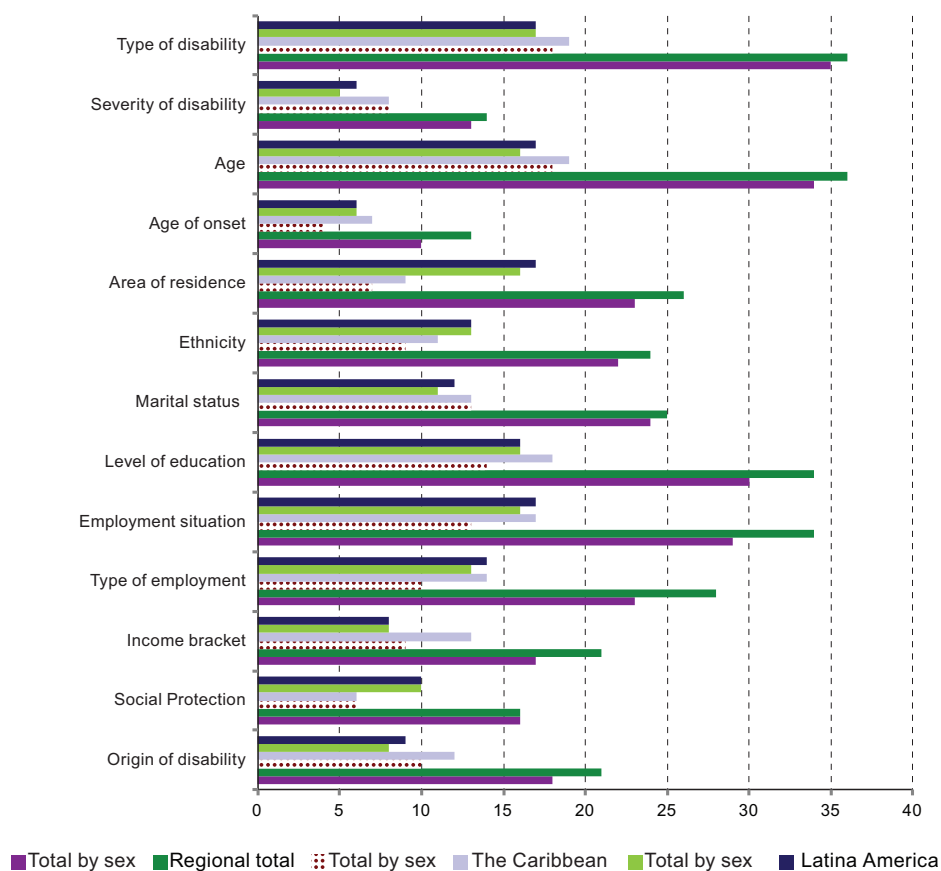
Country	Type of disability	Severity of disability	Age	Age of onset	Area of residence	Ethnic/racial background	Marital status	Level of education	Employment status	Type of employment	Income bracket	Social protection	Origin of disability
Guyana	✓	No	✓	S	S	No	No	S	S	S	S	✓	✓
Cayman Islands	✓	No	✓	No	No	No	No	S	S	No	No	No	No
Turks and Caicos Islands	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
British Virgin Islands	✓	No	✓	No	No	✓	✓	✓	✓	No	No	No	✓
Jamaica	✓	✓	✓	No	✓	No	✓	✓	✓	✓	No	✓	No
Montserrat	✓	No	✓	No	No	✓	✓	✓	✓	✓	✓	✓	✓
Saint Kitts and Nevis	S	No	S	✓	No	No	No	No	No	No	No	No	✓
Sint Maarten	✓	✓	✓	No	No	No	✓	✓	✓	✓	✓	No	No
Saint Lucia	✓	No	✓	✓	✓	✓	✓	✓	✓	✓	✓	No	✓
Saint Vincent and the Grenadines	✓	No	✓	No	No	No	No	✓	✓	No	No	No	No
Suriname	✓	✓	✓	No	S	✓	✓	✓	✓	✓	✓	No	✓
Trinidad and Tobago	✓	✓	✓	No	✓	✓	✓	✓	✓	S	S	No	No
The Caribbean total	19	8	19	7	9	11	13	18	17	14	13	6	12
Regional total	36	14	36	13	26	24	25	34	34	28	21	16	21

Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

Note: The letter S indicates that no sex-disaggregated data are available.

The availability of data is very similar across Latin American and Caribbean countries, with the notable exception of area of residence (as this variable is not relevant in most small island States). The other two differences relate to: income bracket (with most Caribbean countries collecting this information (13 out of 19), compared with 8 out of 17 countries in Latin America); and access to social protection (which is collected more extensively in Latin America (10 countries out of 17) than in the Caribbean (6 out of 19)). The gaps are more significant in terms of data disaggregation by sex, which is lacking even more so for the least available categories of data (see figure 2).

Figure 2
LATIN AMERICA AND THE CARIBBEAN (36 COUNTRIES): CATEGORIES OF DATA AVAILABLE BY SEX



Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

Only two of the 36 countries produce statistical data for all 13 variables: Peru, based on information from the 2012-2013 National Specialized Survey on Disability; and Chile with the 2002 census, the 2004 National study of disability in Chile (ENDISC), and the National Socio-economic Survey (CASEN) of 2006, 2009 and 2011. Similarly, other Latin American countries use the three types of information source (census, household survey and specific survey), depending on each individual country. Argentina, Brazil, Ecuador, and Mexico are the countries with the next lowest number of gaps (one or two), followed by Costa Rica, Cuba, Guatemala and Panama (three gaps). Cuba has the least

amount of information available, as its data are restricted to more traditional population variables, such as type of disability, age, area of residence, employment status and access to social protection.

The fact that population and housing censuses are practically the only source of information available in the Caribbean is part of the reason for more repeated information gaps there than in Latin America (where most countries have carried out some kind of sample survey —see table 4). The only country to provide all the information requested (apart from the area of residence, which is irrelevant in most Caribbean countries) was Bermuda. Bahamas, Barbados, Saint Lucia, Suriname and Turks and Caicos Islands were the countries with the next most complete systems, followed by Guyana, Montserrat and Trinidad and Tobago. The Cayman Islands, Saint Kitts and Nevis and Saint Vincent and the Grenadines are those that need the most support for strengthening their information-collection capacities (as there are over four variables for which they have no information, and often without sex disaggregation): type of disability and age in all three countries; level of education and employment status in the Cayman Islands and Saint Vincent and the Grenadines; and the origin of the disability and age of onset of disability in Saint Kitts and Nevis. One possible explanation for this lack of information is that, with the exception of the Cayman Islands, these countries have not completed the processing of the 2010 round of census and therefore have not been able to supply those data.

D. INSTITUTIONS RESPONSIBLE FOR COLLECTING DISABILITY DATA

Even though the national statistical offices in all the region's countries are the main collectors of statistical information (particularly when it comes to censuses and household surveys), they may not be the governmental agency mandated to be in charge of gathering data on disability. At present, over half of countries that contributed to this report have assigned this responsibility to national statistical offices: 19 out of 36 countries (8 in Latin America and 11 in the Caribbean) (see table 6 and annex 3).

In most other countries (seven Latin American ones and three in the Caribbean), this task has been assigned to national mechanisms responsible for coordinating disability policies. In Latin America (except in El Salvador), this mandate often goes hand in hand with the production of disability information sources in addition to censuses (such as representative surveys in Argentina, Chile, Costa Rica, Dominican Republic and Guatemala; national registers in Argentina, the Bolivarian Republic of Venezuela and Costa Rica; or administrative records in Argentina, the Bolivarian Republic of Venezuela, Costa Rica and the Dominican Republic). The same can be said of the Caribbean, where Barbados and Guyana are the subregion's only two countries to have generated all three sources of information (while Saint Lucia has a national register).

In four countries, this responsibility comes under the Ministry of Health or Social Affairs (Plurinational State of Bolivia, Sint Maarten, Suriname and Turks and Caicos Islands,), which are also associated with producing additional information on disability —especially in the form of national registers (Plurinational State of Bolivia, Suriname and Turks and Caicos Islands). Suriname included questions on disability in its 2000 household survey, while Sint Maarten plans to include these in its 2015 health survey. Bolivia created its own single administrative register, which comes under the Ministry of Health. In Colombia and the British Virgin Islands, the responsibility is shared by national statistical offices and ministries of health. The census remains the only source of disability information in the British Virgin Islands, while in Colombia the National Administrative Department of Statistics (DANE) helped to create the Ministry of Education's administrative register on disability in 2002, which was then transferred to the Ministry of Health and Social Protection in 2010 (which is also responsible for the national register).

Table 6
**LATIN AMERICA AND THE CARIBBEAN (36 COUNTRIES): AGENCIES RESPONSIBLE
 FOR DATA COLLECTION**

Country	National Office of Statistics	Office responsible for disability	Ministry of health/ social affairs	Shared responsibility ^a
Argentina		√		
Bolivia (Plurinational State of)			√	
Brazil	√			
Chile		√		
Colombia				√
Costa Rica		√		
Cuba	√			
Ecuador	√			
El Salvador		√		
Guatemala		√		
Haiti	√			
Mexico	√			
Panama	√			
Paraguay	√			
Peru	√			
Dominican Republic		√		
Venezuela (Bolivarian Republic of)		√		
Latin America total	8	7	1	1
Aruba	√			
Bahamas	√			
Barbados		√		
Belize	√			
Bermuda	√			
Curaçao	√			
Grenada	√			
Guyana		√		
Cayman Islands	√			
Turks and Caicos Islands			√	
British Virgin Islands				√
Jamaica	√			
Montserrat	√			
Saint Kitts and Nevis	^b			
Sint Maarten			√	
Saint Lucia		√		
Saint Vincent and the Grenadines	√			
Suriname			√	
Trinidad and Tobago	√			
The Caribbean total	11	3	3	1
Regional total	19	10	4	2

Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

^a Shared responsibility between the national statistical office and the Ministry of Health.

^b Although the questionnaire was completed by the Saint Kitts and Nevis Ministry of Sustainable Development, the reply given to the question about the name of the main agency responsible for collecting statistical data was “None”.

In Latin America, there is no link between the production of information and the type of agency overseeing that production, as almost all countries collect data from at least two sources —except Cuba’s National Office of Statistics and Information (ONEI) and El Salvador’s National Council for Comprehensive Care of Persons with Disabilities (CONAIPD). There is, however, a clear link in the Caribbean. With the exception of the national statistical offices in Aruba and Bermuda, all of them have limited themselves to disability questions in population censuses, while all mechanisms responsible for national disability policy and those related to ministries of health have made arrangements concerning at least one additional source (see tables 4 and 6).

In the light of the above, the issue of political responsibility becomes highly relevant for the production of statistical information. In this area, it may be useful to refer to another sphere of statistical production and public policies where the latter cannot progress without precise, reliable information that is comparable over time within and among countries. The subject is violence against women. As with persons with disabilities, “what is not counted does not count”. Indeed, a review of relevant statistical advances in the past decade showed the importance of inter-agency arrangements for making effective progress in measuring violence. This gave rise to consultation processes between institutions responsible for: policymaking, service provision, development aid, information collection and the monitoring of relevant methodological and technical aspects (Alméras et al, 2002). In other words, the very production of statistical information benefits from a dialogue between data users and producers, as shown in the review of the link between information sources on disability and the type of agency responsible for producing such information.

E. PUBLIC DISSEMINATION OF STATISTICAL DATA AND REPORTS

The final essential stage for successful measurement processes is the dissemination of results. Without this, what “has been counted” will not “count” in terms of public policymaking. This area is certainly the least developed in the supply chain of statistics throughout the region (and particularly in the Caribbean). Whereas just over half of countries disseminate census information at least online (10 out of 17 Latin American countries and 11 out of 19 Caribbean countries), only five Latin American countries (Argentina, Brazil, Ecuador, Mexico and Peru) and one Caribbean country (Bermuda) disseminate or publish statistical information on disability from the various sources. There are a few examples of limited dissemination, such as Costa Rica reserving data from the national register and administrative records for internal use, and the British Virgin Islands, Saint Kitts and Nevis, Suriname and Trinidad and Tobago providing information from censuses or sample surveys only on request (see tables 7a and 7b).

Table 7a
LATIN AMERICA (17 COUNTRIES): DISSEMINATION OF OFFICIAL STATISTICAL INFORMATION ON DISABILITY

Country	National registers		Administrative records		Censuses		Sample surveys		Other sources	
	Online publication	Printed publication	Online publication	Printed publication	Online publication	Printed publication	Online publication	Printed publication	Online publication	Printed publication
LATIN AMERICA										
Argentina	√		√		√					
Bolivia (Plurinational State of)			√		√					
Brazil			√		√	√	√	√		
Chile						√	√			
Colombia	√				√	√				
Costa Rica		√ ^a			√		√			
Cuba						√				
Ecuador					√		√	√		
El Salvador										
Guatemala										
Haiti										
Mexico					√			√		
Panama										
Paraguay					√	√				
Peru	√		√		√	√	√	√	√	
Dominican Republic						√				
Venezuela (Bolivarian Republic of)										
Latin America total	3		4	1	10	6	6	6	2	1

Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

Note: Totals only consider public dissemination with no restrictions.

^a Strictly for internal use.

Table 7b
CARIBBEAN (19 COUNTRIES): DISSEMINATION OF OFFICIAL STATISTICAL INFORMATION ON DISABILITY

Country	National registers		Administrative records		Censuses		Sample surveys		Other sources	
	Online publication	Printed publication	Online publication	Printed publication	Online publication	Printed publication	Online publication	Printed publication	Online publication	Printed publication
The Caribbean										
Aruba								√		
Bahamas										
Barbados			√			√				
Belize			√							
Bermuda			√							√
Curaçao			√			√				
Grenada										
Guyana			√							
Cayman Islands										
Turks and Caicos Islands						√				
British Virgin Islands			√			√ ^a				
Jamaica			√			√				
Montserrat			√			√				
Saint Kitts and Nevis			√ ^a							
Sint Maarten										
Saint Lucia			√							
Saint Vincent and the Grenadines										
Suriname			√			√				√ ^a
Trinidad and Tobago			√			√ ^a				√ ^a
The Caribbean total	3	4	21	1	12	6	1	7	1	2
Regional total	3	4	21	1	12	6	1	7	1	2

Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

Note: Totals only consider public dissemination with no restrictions.

^a Provided upon request.

III. MAIN DIFFICULTIES FACING COUNTRIES IN TERMS OF COLLECTING INFORMATION

A. SUMMARY OF FINDINGS

To supplement the information collected by the Task Force, a question was also included on the main difficulties encountered in collecting statistics on the situation of persons with disabilities. The response options were as follows:

- No mandate in this regard
- Lack of government interest in using the information in public policymaking
- Lack of budget
- Lack of qualified human resources in this field
- Limited validity of sample size
- Lack of capacity to analyse data collected
- Lack of clarity on the appropriate channels for disseminating the information
- Other

Out of the region's 36 countries that took part in the survey, one quarter left this question blank (Argentina, Brazil, El Salvador and Panama in Latin America; and the Bahamas, Grenada, Saint Vincent and the Grenadines and Suriname² in the Caribbean). Of the 27 countries that responded (13 out of 17 Latin American countries; and 14 out of 19 Caribbean countries), three quarters (20 countries) cited lack of budget as the main obstacle (particularly in the Caribbean, with 12 out of 14 countries). In the Caribbean, only Barbados and Trinidad and Tobago did not mention budget. Less significant difficulties in a third of countries included "lack of qualified human resources" (8 countries, including 6 in the Caribbean), lack of mandate (8 countries, 5 in the Caribbean) and conceptual and operational difficulties (8 countries, 5 in Latin America) (see tables 1a) and 1b)).

The final item warrants a special mention, as it is the consolidation of the difficulties listed by the eight countries that ticked the "Other" category. These conceptual and operational difficulties cover a series of limitations that point to the current concern of countries to produce quality data in a field of knowledge in its infancy. The first series of comments refer to the methodological and operational difficulties relating to the understanding, operationalization and analysis of the new concept of disability (Chile and Ecuador). The second set of remarks relates to the limits of reported information, which depends on whether responses to the survey are self-reported or given by a third party, which can lead to under-recording or over-recording (Cuba and the Bolivarian Republic of Venezuela). Mexico cited the lack of statistical projects on the subject, which might reflect a lack of collaboration among the various relevant counterparts, as mentioned by Curaçao in the Caribbean. In that same region, the British Virgin Islands and Sint Maarten emphasized the lack of collection instruments beyond censuses —which they relate to the lack of mandates specifically for collecting information on disability.

In order of frequency, the other difficulties mentioned are: limited validity of sample size (5 countries, 3 in Latin America) —which is understandable in a region with several small and sparsely

² In its questionnaire response, Suriname did not give an answer but stated "Not applicable, N/A" under "Other" (with no further explanation provided).

populated countries; lack of capacity to analyse information collected (5 countries, 3 in the Caribbean); and one that could combine with the previous one— lack of qualified human resources, as mentioned by four of the countries that cite such problems (Costa Rica, Belize, Montserrat and Saint Kitts and Nevis). These two reasons were not associated by Paraguay or Jamaica. Only three countries referred to a lack of government interest in using the information produced for public policymaking: Mexico in Latin America and Belize and Guyana in the Caribbean. This final point could refer to a situation where efforts to build a good relationship between producers and users of statistical information on disability are under way.

B. LINK BETWEEN TYPE OF DIFFICULTIES AND IMPLEMENTATION OF INTERNATIONAL GUIDELINES

By asking about problems in data production, one of the objectives of the SCA Task Force is to try to understand the obstacles to a full application of international recommendations on disability measurement. This is why the two subjects were combined in the same table for comparison (see tables 1 a) and 1 b)).

Contrary to expectations, it is not possible to link a particular difficulty with a given result. For instance, out of the 20 countries that identified the common obstacle (“lack of budget”), nine do use the three sets of international guidelines proposed by the United Nations system (the Washington Group brief questionnaire; the International Classification of Functioning, Disability and Health; and the Guidelines and Principles for the Development of Disability Statistics). Five of the nine are in Latin America (Chile, Dominican Republic, Mexico, Paraguay and Peru), while four are Caribbean countries (Aruba, Guyana, Jamaica and Saint Lucia).

Analysis of the application of recommendations one by one shows that, out of the eight Latin American countries that mention “lack of budget”, all of them have applied the recommendations of the International Classification of Functioning, Disability and Health and the Guidelines and Principles for the Development of Disability Statistics in at least some cases³ (with five countries also using the Washington Group questions). In the Caribbean, there could be said to be a link between difficulty and lack of compliance: out of the 12 countries that cited “lack of budget” as an obstacle, only four apply all recommendations. Lastly, 8 out of 12 countries included Washington Group questions in the most recent census or specific survey, six countries used the International Classification as a reference, and another six countries used the Guidelines and Principles.

The difference between Latin American and Caribbean countries becomes apparent when it comes to assessing the number of obstacles identified by each country. In Latin America, countries reporting at least three difficulties are those that apply all international recommendations and do not use censuses alone to collect information (Chile, Costa Rica, Mexico and Paraguay). However, other Latin American countries that also apply all recommendations and use other instruments either have no difficulties (Argentina and Brazil) or just budgetary problems (Dominican Republic and Peru). This suggests that these are not hindrances as such, but rather an awareness of the range of obstacles in the way of progressing even further.

³ Guatemala does not yet apply the international recommendations, but has planned to do so in the census scheduled for 2015.

Precisely the opposite is true in the Caribbean, except for Saint Lucia (which also follows all international recommendations). Countries reporting three or more difficulties (Belize, Montserrat and Saint Kitts and Nevis) do not widely observe the guidelines and only have censuses as sources of information on disability. The other two countries that follow international guidelines and have created information sources in addition to censuses (Aruba and Guyana) both cite budget as a problem, plus the lack of government interest in the case of Guyana (which is similar to countries in Latin America).

One possible reason is the assumption that the difficulties seem more intense at two moments of statistical production: the beginning (fighting initial inertia), and then using a variety of collection instruments as a basis for progressing onto creating a coherent and stable information system. Based on this assumption, and in the light of the total number of difficulties reported in the Caribbean (33) compared with Latin America (24), this suggests a greater need for support to strengthen the production of statistical information on disability in the Caribbean.

C. LINK BETWEEN TYPE OF DIFFICULTY AND QUALITY OF INFORMATION COLLECTED

While it is not possible to establish a link between breadth of information gathered and the presence or absence of difficulties, there is a cause-and-effect link with the application of at least two of the international recommendations (see tables 1 and 3). The number of gaps in the information collected increases in inverse proportion with the decreasing level of compliance with the three sets of guidelines.

This link is weaker in the Caribbean than in Latin America: the former has countries following one set of international guidelines and collecting information with few gaps (Bahamas, Curaçao, Grenada and Trinidad and Tobago). However, these examples may be the exceptions that prove the rule. In both regions, the other countries with a low level of compliance with Washington Group recommendations, ICF or the International Guidelines and Principles have less data available in the categories assessed herein (Cuba in Latin America; and Belize, British Virgin Islands, Cayman Islands, Saint Kitts and Nevis and Saint Vincent and the Grenadines in the Caribbean).

In terms of possible links between difficulties and the agencies responsible for producing information, the data suggest no specific pattern that highlights any determining factor. The same difficulties (or lack thereof) are apparent irrespective of the agency origin, be it national statistical office, mechanism monitoring the situation of persons with disabilities, ministry of health or ministry of social affairs.

In order to understand the factors underlying the difficulties of data collection, it would be useful to take a closer look at the institutional arrangements among the various bodies involved in the chain of producers, users and policymakers. This would probably reveal dynamics that result in a shortage of certain resources essential for building quality information systems: political will; sufficient human and financial resources; relevant technical and analytical capacity; and up-to-date methodological tools suited to the national demographic situation. Care must also be taken to arouse the interest of users (civil society, academia and government) through well-organized dissemination. This will enable those users to use the data in their respective sectors: advocacy and monitoring; accumulation of knowledge; design of programmes and policies and follow-up of services needed by the population.

CONCLUSIONS

An analysis of this first part of the regional report “Overview of the Disability Measurement Procedures in Latin America and the Caribbean” identifies the integration of international guidelines on statistical procedures as a determining factor for generating positive results. Applying any of the relevant instruments (Washington Group brief questionnaire; the International Classification of Functioning, Disability and Health (ICF); and the Guidelines and Principles for the Development of Disability Statistics) has a positive effect on: (1) quality of information for measuring the scale and prevalence of disability in the country; (2) coherence between the concept of disability used as a basis for measurement and the operationalization of the collection instrument; and (3) the quantity of information that can be obtained and disaggregated to improve the profiling of this population group. However, this would be even more productive if based on an information system incorporating all three sets of guidelines.

A second extremely relevant factor relates to specific studies carried out using other sources to supplement census information. Random and representative surveys provide in-depth exploration of the issues faced on a daily basis by people living with some form of disability. This knowledge is essential for devising public policies that are adapted to each country’s situation, at the local and national levels.

There is therefore also a need to improve national and administrative records to create a comprehensive information system, namely one that combines information sources that mutually complement and reinforce one other. National records are vital for identifying the location of persons with disabilities, which is a prerequisite for creating a network of services tailored to the various needs of people with different forms of disability, in a context where many people’s limited autonomy and mobility would prevent their accessing services far from where they live. Administrative records help monitor the state of and demand for services, ideally through agreements among all institutions providing services. This would involve harmonized protocols for care and referral to other centres, thereby standardizing information recorded in order to: 1) identify the scale of problems and how they are tackled; 2) quantify the evolution of needs and make projections; 3) compare data within one institution over time in order to make the necessary adjustments (including a change in collection criteria); and 4) compare the development of needs and the responses among services in different parts of the country.

The information collected in the 36 countries that took part in this study shows clear signs of the need to undertake efforts to strengthen and train agencies responsible for collecting disability data, with a view to strengthening the implementation of these two major components of disability measurement procedures (in the region and worldwide). As well as providing the parameters for implementing various data-collection instruments, attention should also be given to the conceptual, methodological and operational difficulties identified as part of this research (and particularly those related to the understanding, operationalization and analysis of the new concept of disability).

This suggests that national statistical offices and other agencies responsible for collecting information on disability should reach a joint and coordinated definition of the technical and analytical capacities required by their statistical teams. Also relevant in this regard are horizontal cooperation initiatives involving Latin American and Caribbean countries. For instance, one current example for other countries to follow is provided by Argentina and Peru, which have achieved good results in terms of complying with international recommendations, having a wide range of available data, implementing representative surveys, maintaining both types of records and disseminating data from most of their information sources. In the Caribbean, Bermuda and Suriname are the countries that come closest to being able to produce information systems with these characteristics in the short term.

The dissemination and analysis of the statistical information collected from early 2014 for the second part of this regional report, which will be presented at the next session of the ECLAC Statistical Conference of the Americas, will also be useful for future training activities. This is the first time that such a data set has been gathered on persons with disabilities in Latin American and Caribbean countries, and disseminating such information could result in a regional database accessible to many diverse users. The data will also reveal the scale, prevalence and trends of the situation of a group of people whose requirements are not yet being met and who represent an ever-increasing proportion of the population.

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Annex 1

**OFFICIAL SOURCES OF INFORMATION ON DISABILITY INCLUDED IN THE REPORT,
LATIN AMERICA AND THE CARIBBEAN (40 COUNTRIES)**

LATIN AMERICA

- Argentina: - National Survey on Persons with disabilities (ENDI), 2002/2003 and National
- Population, Household and Housing Census, 2010;
- Bolivia (Plurinational
State of): - Population and Housing Census, 2012;
- Brazil: - National Household Sample Survey, 1991 and 1998
- School Census (from 1999)
- Population Census, 2010 and 2012;
- Chile: - 17th National Population Census, 6th Housing Census, 2002,
- National Disability study (ENDISC), 2004;
- National Socio-economic Survey (CASEN) of 2006, 2009 and 2011
- Colombia: - Population and Housing Census, 2005;
- Costa Rica: - 10th National Population Census and 6th Housing Census, 2011
- National Household Survey (ENAHO), 2010 and 2013;
- Cuba: - Population and Housing Census, 2012;
- Dominican Republic: - 8th National Population and Housing Census, 2002
- National Multipurpose Household Survey (ENHOGAR), 2006 and 2013;
- Ecuador: - Employment, Underemployment and Unemployment survey, 2004
- Living Conditions Surveys, 2006 and 2014 (under way)
- Population and Housing Census, 2010;
- El Salvador: - 6th Population Census and 5th Housing Census, 2007;
- Guatemala: - Population and Housing Census, 2002 and
- National Disability Survey (ENDISC), 2005;
- Haiti: - General Population and Housing Census, 2003
- 2012 Post-Earthquake Living Conditions Survey (ECVMAS) ;
- Honduras: - 11th National Population Census and 6th Housing Census, 2002;
- Mexico: - Population and Housing Census, 2010 (extended questionnaire) and National -
Household Income and Spending Survey (ENIGH), 2012;
- Nicaragua: - National Disability Survey (ENDIS), 2003;
- Panama: - Population and Housing Census, 2010;
- Paraguay: - National Population and Housing Census, 2012;

- Peru: - Population and Housing Census, 2007 (information by household)
 - Specialized National Disability Survey, 2012
 - 2012 Census on persons with disabilities in the Department of Tumbes;
- Uruguay: - National Population Census, 2011;
- Venezuela (Bolivarian Republic of): - Population and Housing Census, 2011;

THE CARIBBEAN

- Antigua and Barbuda: - Population and Housing Census, 2001
- Aruba: - Health Survey, 2006
 - Population and Housing Census, 2010
- Bahamas: - Population and Housing Census, 2010
- Barbados: - Population and Housing Census, 2010
 - Specific Surveys by the National Disability Unit (no date)
- Belize: - Population and Housing Census, 2010
- Bermuda: - Seniors Test for Ageing Trends and Services Survey, 2007
 - National Survey of People who are Blind/Visually Impaired, 2009
 - Population and Housing Census, 2010
- British Virgin Islands: - Population and Housing Census, 2001
- Cayman Islands: - Population and Housing Census, 2010
- Curaçao: - Population and Housing Census, 2011
- Grenada: - Population and Housing Census, 2001
- Guyana: - Population and Housing Census, 2002
 - Specific survey, 2005
- Jamaica: - Population and Housing Census, 2011
- Montserrat: - Population and Housing Census, 2011
- Saint Kitts and Nevis: - Population and Housing Census, 2001
- Saint Lucia: - Population and Housing Census, 2010
- Sint Maarten: - Population and Housing Census, 2011
- Saint Vincent and the Grenadines: - Population and Housing Census, 2001
- Suriname: - Multiple Indicator Cluster Survey, 2000
 - Population and Housing Census, 2012
- Trinidad and Tobago: - Survey of Living Conditions, 2005 and 2014 (under way)
 - Population and Housing Census, 2011
- Turks and Caicos Islands: - Population and Housing Census, 2012

Annex 2

**DEFINITIONS OF “DISABILITY” USED IN THE COLLECTION OF INFORMATION
IN LATIN AMERICA AND THE CARIBBEAN (33 COUNTRIES)⁴**

LATIN AMERICA

- Argentina: Disability is any limitation on activity and restriction on participation that originates in an impairment (for instance in seeing, hearing, walking, learning, etc.) and that affects a person permanently in carrying out their daily lives in their physical and social environment (for example in education, recreation, work, etc.) **IMPORTANT:** the difficulty or limitation must be current: it must be affecting the individual at the time of the interview. It must be permanent: it should last over time (more than a year). This excludes short-term disabilities resulting from temporary conditions such as disease or fractures. The following are included: People aged 65 or more who suffer from a permanent disability that originated in an impairment (even if the latter is not clearly defined or is due to degenerative processes in which age plays a crucial role); all people with permanent disabilities (even if they have overcome this with the use of some external technical aid such as crutches, wheelchair, prosthetic limb, hearing aid, oxygen, catheters, etc.); all people with internal technical aids such as pacemakers, cardiac valve implants, pins, etc. or people with an organ transplant, who are limited in carrying out some activities of daily life and experience restrictions on participation (even with this type of aid). Includes people waiting for an organ transplant.
- Bolivia (Plurinational State of): According to Law 1678 on persons with disabilities: this means any restriction or absence —due to an impairment— of the ability to carry out an activity in the way or within the range considered normal for a human being.
- Brazil: The concept of disability used in the 2010 Population Census followed the recommendation of the Washington Group or is based on the International Classification of Functioning, Disability and Health.
- Chile: **1. Definition from National Law on Disability No. 19.284 on the social integration of persons with disabilities:** According to Article 3(1) of Law No. 19.284 on the social integration of persons with disabilities "For the purposes of this law, persons with disabilities shall be considered to be those who, as a result of one or more physical, psychological or sensory impairments, congenital or acquired, that are predictably permanent, irrespective of the original cause, are hampered (by at least a third) in their capacity for educational, labour-market or social integration. According to the World Health Organization (WHO) in its

⁴ Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

1980 International Classification of Impairments, Disabilities and Handicaps (ICIDH), a disability is any restriction or absence —due to an impairment— of the ability to carry out an activity in the way or within the range considered normal for a human being. In the new International Classification of Functioning, Disability and Health, adopted in 2001, disability is an umbrella term for deficits, limitations on activity and restrictions on participation. It refers to negative aspects of the interaction between the individual (with a health condition) and individual contextual factors (environmental and personal factors).

2. Definition from the 2012 Census, according to Washington Group recommendations and the guidelines from the UN 2010 round of censuses:

The census question on disability focuses on limitations to the basic functions of life in the sensory, physical and cognitive spheres. According to the Washington Group guidelines, the set of questions was tested in terms of the two areas: difficulties and functions.

Colombia: DANE defines people with and/or in a situation with disabilities as those persons with medium- or long-term physical, mental, intellectual or sensory impairments that, in the interaction with various barriers (including attitudes), may prevent their full and effective participation in society in equal conditions to other people.

For the Ministry of Health and Social Protection, the definition is based on the international standards of the United Nations and the International Classification of Functioning: “disability is an evolving concept and that disability results from interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (Convention on the Rights of Persons with Disabilities, 2006).

Costa Rica: The concept of disability used to collect statistics in the 2011 Census and the National Household Survey (ENAHO) was a version of the Washington Group recommendation: the result of the interaction between people with impairments and barriers due to attitudes and the environment that limit their full participation in society in equal conditions to other people; and that also have a negative impact on their autonomy and development for carrying out one or more of their basic activities. In operational terms, the research for the Household Survey was based on identifying the presence of permanent limitations by function. In other words, identifying the people with a permanent form of limitation or disability that hampers or prevents them from carrying out their daily activities. These limitations may be congenital (from birth) or acquired (through disease or accident).

Cuba: For the purposes of research carried out in this country, “disability” was considered to be any serious limitation in carrying out the activities of daily life, including those people who reduced or eliminated their disability with the use of external technical aids (if they would find it difficult to carry out daily activities independently without such aids).

Dominican Republic: Defined as a physical, mental or sensory impairment —permanent or temporary— that limits the capacity for one or more essential activities of daily life that may be caused or aggravated by the economic and social environment.

Definition included in the interviewers' handbook: any restriction or impediment to the ability to carry out an activity in a way or within a range considered normal for a human being.

- Ecuador: The definition of disability has changed over time and in accordance with statistical operations. Generally speaking, the questions from the 2014 Living Conditions Survey are comparable with those from the 2010 Population Census (as well as additional questions relating to special education and functionality, among others). According to the Population and Housing Census, 2001: Permanent incapacity of a physical, sensory or mental kind (disability) is a permanent difficulty in carrying out an activity considered normal, due to the irreversible effects of a congenital or acquired incurable disease Population and Housing Census, 2010: Disability means any limitation on activity and restriction in participation that originates in a permanent impairment that affects people in carrying out their daily life in their physical and social environment. Living Conditions Survey, 2014: a person with disability is considered to be anyone who—as a result of one or more physical, mental, intellectual or sensory impairments (irrespective of the original cause)—has his/her biological, psychological and associative capacity to carry out one or more essential activities of daily life permanently restricted (Art. 6 of the Disabilities Act).
- El Salvador: The criteria followed were those established by WHO-PAHO in the International Classification of Functioning, researching peoples' limitations on activity and restrictions on participation. The definition used follows the United Nations Convention on the Rights of Persons with Disabilities.
- Guatemala: The National Disability Survey (ENDIS-2005) was changed in that year for budgetary reasons, on the basis of international recommendations and the methodological criteria and definitions of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which was recommended by the United Nations Manual on the Development of Disability Statistics, as well as the International Classification of Diseases (ICD-10). The definition of disability in ENDIS-2005 considered any serious limitation currently suffered by a person and permanently affecting the activity of the individual. It should have its origin in an impairment that permanently affects the person carrying out his/her daily life in his/her physical and social environment. There is, however, an exception made for a few disabilities that do not originate in a defined impairment, but rather are due to degenerative processes in which the person's age plays a decisive role. This is the case of children aged under 6, who were previously considered to have limitations and not disabilities.
- Haiti: A disability reflects any limitation or lack of ability that a person experiences in performing an activity as learning, speaking, walking or some other activity. Disability involves the interaction of a person's functional status with his/her physical, cultural and policy environment. Source: Documentation for the Fifth Population and Habitat Census to be held in 2014.
- Mexico: Generic term that includes impairments in the structures and functions of the human body, limitations on the personal ability to carry out basic tasks of daily

life and restrictions on social participation experienced by the individual when involved in situations within his/her environment.

- Panama: Any restriction or absence (due to an impairment) of the capacity to carry out an activity in a way or within the range considered normal for a human being.
- Paraguay: Any limitation on activity and restriction on participation due to an impairment permanently affecting a person in carrying out his/her daily life within his/her physical and social environment.
- Peru: Article 2 of the new Act on Persons with Disabilities, Law No. 29973, published on 24 December 2012, defines a person with a disability as follows: “with one or more permanent physical, sensory, mental or intellectual impairments that, in the interaction with various barriers (including attitudes) may hamper or prevent the exercise of their rights and their full and effective participation in society in equal conditions to other people.” This definition has not yet been used in data-collection processes, as these were carried out prior to the publication of the new Law.
- Venezuela (Bolivarian Republic of): Law on Persons with Disabilities, Official Gazette No. 38598: Art. 5.—Disability shall be understood as the complex human condition made up of bio-psychosocial factors that involves a temporary or permanent reduction or removal of some sensory, motor or intellectual capacities that may manifest in absences, anomalies, defects, losses or difficulties in perceiving, moving without support, seeing or hearing, communicating with others or taking part in education and work activities, in the family and community, and that limit the exercise of rights, social participation and the enjoyment of a good quality of life or prevent people’s active participation in family and social life (without necessarily meaning incapacity or inability to integrate socially).

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- Aruba: Handicapped persons are persons with a physical or mental disorder. The handicap is formed by the limitations of the personal abilities due to the disorder. Handicapped persons do not include individuals who are recovering from an illness or accident and who will be cured within a limited period. Their perspective is, after all, to be completely healed.
- Bahamas: Persons who have long-term physical, mental, intellectual, sensory impairments or health-related conditions, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.
- Barbados: 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 or mental condition or health problem. Only disabilities lasting for more than six months are included.

- Belize: According to our Census manuals, the definition used for disability is a difficulty or impairment with any of the following: sight, hearing, speech, mobility and body movement, learning and behaviour, and self-care. The difficulty or impairment should either have been continuous for at least six months prior or likely to last six months or more into the future. It is important to note that these figures are all self-reported during the Census. There was no medical evidence of the disability required, just what the respondents reported. Also, a person could have reported multiple impairments.
- Bermuda: Disability is an umbrella term that refers to problems, such as impairment, activity limitation or participation restrictions that indicate the negative aspects of functioning (Washington Group). A long-term health condition that lasts (or is expected to last) for more than six months and limits or prevents any of a person's everyday life activities (e.g. work, recreation, mobility and schooling).
- British Virgin Islands: A disability or infirmity is long-standing, that is, the person has had the condition for six months or more and it is not of a temporary nature. It is permanent, regardless of how long ago it manifested itself (this was the definition used to guide enumerators during the 2001 census exercise).
- Cayman Islands: Inability or great difficulty in performing one or more major life activity in the person's current social environment because of impairment, e.g. missing, damaged or weakened body part or function.
- Curaçao: In the Census of 2011 the approach of the Washington Group on Disability Statistics was used.
- Guyana: Disability as defined in the Guyana Disability Act 2010 means: a physical or mental impairment caused by the limitations of the body structure or of one or more bodily functions that restrict the ability to perform ordinary day-to-day life activities.
- Jamaica: Data on the topic have been collected by the Statistical Institute of Jamaica in the decennial population censuses only since 1991. For 2011, the most recent census, no specific definition was used; in fact, the word disability was not used. The line of questioning followed the approach recommended by the Washington Group with the use of the short set of questions. The published data reflect the responses to these questions with no specific group being identified as disabled.
- Montserrat: Disability is a long-standing condition that has lasted more than 6 months or is expected to last more than one year. The condition can hamper or reduce the individual's ability to carry out day-to-day activities and require daily living adaptations.

- Saint Kitts and Nevis: The definition of persons with disabilities is extracted from the United Nations Principles and Recommendations for Population and Housing Censuses Revision 2 (2008; page 178; item 2.351). Persons with disabilities are defined as those persons who are at greater risk than the general population for experiencing restrictions in performing specific tasks or participating in role activities. The main domains of disabilities are walking, seeing, hearing and cognition.
- Saint Lucia: A person who is disabled is a person unable to function or incapable of functioning in society as a result of an impairment.
- Sint Maarten: Sint Maarten uses the short set of the disability questions of the Washington Group.
- Suriname: The Dutch translation “functionerings probleem” from CIF is used (WHO FIC Collaborating Centre, 2002).
- Trinidad and Tobago: Persons with disabilities are defined as those persons who are at greater risk than the general population for experiencing restrictions in performing specific tasks or participating in role activities. Disabilities lasting for or expected to last at least six months are included.

Annex 3

**AGENCIES RESPONSIBLE FOR COLLECTING STATISTICAL DATA ON DISABILITY
IN LATIN AMERICA AND THE CARIBBEAN (36 COUNTRIES)⁵**

LATIN AMERICA

Argentina:	National Advisory Commission for the Integration of Persons with Disabilities (CONADIS)
Bolivia (Plurinational State of):	Ministry of Health and Sport
Brazil:	Brazilian Institute of Geography and Statistics (IBGE)
Chile:	National Disability Service (SENADIS)
Colombia:	Ministry of Health and Social Protection and National Administrative Department of Statistics (DANE)
Costa Rica:	National Council on Rehabilitation and Special Education (CNREE)
Cuba:	National Office of Statistics and Information (ONEI)
Dominican Republic:	National Disability Council (CONADIS)
Ecuador:	National Statistics and Census Institute (INEC)
El Salvador:	National Council for the Comprehensive Care of Persons with disabilities (CONAIPD)
Guatemala:	National Council on Disability (CONADI)
Haiti:	Haitian Institute of Statistics and Informatics (IHSI)
Mexico:	National Institute of Statistics and Geography (INEGI)
Panama:	Statistics and Census Bureau, Office of the Comptroller General
Paraguay:	General Directorate of Statistics, Surveys and Censuses (DGEEC)
Peru:	National Institute of Statistics and Informatics (INEI)
Venezuela (Bolivarian Republic of):	National Council for Persons with Disabilities (CONAPDIS)

⁵ Source: Economic Commission for Latin America and the Caribbean (ECLAC), on the basis of surveys on disability measurement in Latin America and the Caribbean carried out by the Commission in 2014.

THE CARIBBEAN

Aruba:	Central Bureau of Statistics (CBS)
Bahamas:	Ministry of Finance - Department of Statistics
Barbados:	National Disability Unit
Belize:	Statistical Institute of Belize
Bermuda:	Department of Statistics, Cabinet Office
British Virgin Islands:	Central Statistics Office or Ministry of Health and Social Development
Cayman Islands:	Economics and Statistics Office
Curaçao:	Central Bureau of Statistics
Grenada:	Central Statistical Office
Guyana:	National Commission on Disability
Jamaica:	Statistical Institute of Jamaica
Montserrat:	Statistics Department - Ministry of Finance & Economic Management (MoFEM)
Saint Kitts and Nevis:	None
Saint Lucia:	National Council of and for Persons with Disabilities
Sint Maarten:	Ministry of Health, Department of Statistics (STAT)
Saint Vincent and the Grenadines:	Statistical Office, Central Planning Division
Suriname:	Ministry of Social Affairs
Trinidad and Tobago:	Central Statistical Office (CSO), Ministry of Planning and Sustainable Development
Turks and Caicos Islands:	Ministry of Health and Social Services